



Prostate Cancer  
Foundation of Australia



Australian Research Centre  
in Sex, Health and Society

# PROSTATE CANCER INFORMATION NEEDS OF AUSTRALIAN GAY AND BISEXUAL MEN

---

OCTOBER 2013

MONOGRAPHS IN  
PROSTATE CANCER

# OUR VISION, MISSION AND VALUES

**Prostate Cancer Foundation of Australia (PCFA) is a broad-based community organisation and the peak national body for prostate cancer in Australia. We are dedicated to reducing the impact of prostate cancer on Australian men, their partners, families and the wider community.**

We 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.

PCFA receives Government funding for specific projects and relies on the generosity of individuals, the community and partnerships, such as those with The Movember Foundation and Commonwealth Bank, to carry out our essential work.

---

## **Suggested citation:**

Wong, W.K.T., Lowe, A., Dowsett, G.W., Duncan, D., O'Keeffe, D., & Mitchell, A. (2013). Prostate cancer information needs of Australian gay and bisexual men. Sydney: Prostate Cancer Foundation of Australia.

ISBN: 978-0-9923335-8-4

## **Copies of this monograph can be obtained by contacting:**

**Prostate Cancer Foundation of Australia  
Level 3, 39-41 Chandos Street  
St Leonards NSW 2065 Australia**

**Postal Address: GPO Box 1332, Lane Cove, NSW, 1595 Australia**

**Telephone: +61 2 9438 7000 / 1800 22 00 99 (freecall)**

**Email: [enquiries@pcfa.org.au](mailto:enquiries@pcfa.org.au)**

**Web: [www.pcfa.org.au](http://www.pcfa.org.au)**

## **Copyright © Prostate Cancer Foundation of Australia 2013**

This work is copyright. Apart from any use as permitted under the Copyright Act 1968, no part may be reproduced by any process without written permission from Prostate Cancer Foundation of Australia. Requests and enquiries concerning reproduction and rights should be addressed to the Chief Executive Officer, Prostate Cancer Foundation of Australia, GPO Box 1332, Lane Cove, NSW, 1595, Australia.

Website: [www.pcfa.org.au](http://www.pcfa.org.au) Email: [enquiries@pcfa.org.au](mailto:enquiries@pcfa.org.au)

Photography: Gavin Jowitt

# PROSTATE CANCER INFORMATION NEEDS OF AUSTRALIAN GAY AND BISEXUAL MEN

---

**W.K. Tim Wong<sup>1</sup>**

**Anthony Lowe<sup>1,3</sup>**

**Gary W. Dowsett<sup>2</sup>**

**Duane Duncan<sup>2</sup>**

**David O’Keeffe<sup>2</sup>**

**Anne Mitchell<sup>2</sup>**

<sup>1</sup> Prostate Cancer Foundation of Australia

<sup>2</sup> Australian Research Centre in Sex, Health & Society, La Trobe University

<sup>3</sup> Griffith Health Institute , Griffith University

# ACKNOWLEDGEMENTS

## **We acknowledge the following individuals and organisations for their contribution:**

### **Participants**

We thank the men in the focus groups for their time and willingness to share their experiences.

### **Australian Research Centre in Sex, Health & Society (La Trobe University)**

We thank Jan Watson and Andrew Westle for research support and assistance.

### **Malecare (USA)**

We thank our partner organisation, Malecare ([www.malecare.org](http://www.malecare.org)), for the use of information and materials provided by them in this report.



### **Cancer Australia**

One of the two studies commissioned by PCFA and reported in this monograph was made possible through the *Supporting men with prostate cancer through evidence-based resources and support* project – a Cancer Australia initiative funded by the Australian Government.

# CONTENTS

---

FOREWORD	1
INTRODUCTION	2
STUDY 1: AN AUDIT OF EXISTING RESOURCES AND WEBSITES PROVIDING INFORMATION TO GAY AND BISEXUAL MEN WITH PROSTATE CANCER	5
STUDY 2: AN EXAMINATION OF THE PROSTATE CANCER HEALTH INFORMATION RESOURCES AND PROMOTION NEEDS OF AUSTRALIAN GAY AND BISEXUAL MEN	9
DISCUSSION	17
REFERENCES	21
APPENDIX	26

---

# FOREWORD

**In spite of the vast amount of research into prostate cancer, sexual orientation is not a piece of information that is routinely collected in cancer registries, nor is it usually asked of men who participated in prostate cancer research studies, which means there is a lack of clarity about the experiences of gay and bisexual men with prostate cancer and uncertainty about their information needs relating to this health issue.**

In redressing this situation, Prostate Cancer Foundation of Australia (PCFA) commissioned the Australian Research Centre in Sex, Health and Society (ARCSHS), at La Trobe University, to conduct two studies.

- An audit of existing resources and websites providing prostate cancer information catering to the needs of gay and bisexual men.
- An examination of the prostate cancer health information resources and promotion needs for Australian gay and bisexual men.

Findings from these studies show that there is a dearth of information materials and resources specifically for gay and bisexual men, and information that is particular and pertinent to gay and bisexual men is either inadequate or absent. The language and imagery used in existing information materials overwhelmingly reflects heterosexuality, and gay and bisexual men are not included in the information even though they are more likely than heterosexual men to experience the

impact of prostate cancer because of the possibility that one or both partners in a same-sex relationship could be diagnosed with it.

Informed by these findings, and in partnership with Malecare, PCFA, through its Gay and Bisexual Men's Prostate Cancer Initiative, has established five support groups specifically for gay and bisexual men in Adelaide, Brisbane, Melbourne, Perth and Sydney. Work has commenced to establish more gay and bisexual men's support groups in Darwin and Hobart.

Moreover, PCFA is developing a set of resources for gay and bisexual men that provide information on a range of issues relating to prostate cancer specifically written and designed for this population. These resources are explicitly for gay and bisexual men, culturally appropriate and written in plain non-medical language to inform them of the diagnostic process, potential impact of prostate cancer and treatment on their social and sexual lives, as well as support and wellbeing issues following diagnosis and treatment. More importantly, the information needs of gay and bisexual men identified in the studies are addressed in these resources. PCFA positions these resources as parts of the process of illuminating and redressing the inadequate attention to gay and bisexual men's information needs pertaining to prostate cancer health.

This report is one of the few research-based documents on prostate cancer that places gay and bisexual men as its prime focus. We trust you will read with interest, and join with PCFA in its endeavour to reduce the impact of prostate cancer on Australian gay and bisexual men, their partners, families and friends through research, awareness and support.

# INTRODUCTION

Prostate cancer is the second most commonly diagnosed cancer and the sixth leading cause of cancer death in men worldwide<sup>[1]</sup>. In Australia, prostate cancer is the most common non-skin cancer in the male population<sup>[2]</sup>, and accounts for 25-30% of cancers diagnosed each year in men<sup>[3]</sup>. In 2009, more than 19,400 new diagnoses were reported, and in 2010, there were more than 3,200 deaths from prostate cancer accounting for 5% of all deaths and 13% of cancer-related deaths among men aged 25 and over<sup>[4]</sup>, which places it as one of the most common causes of cancer death in 2010 (second to lung cancer)<sup>[5]</sup>. It is anticipated that prostate cancer will continue to be the most common cancer diagnosed in men in 2020<sup>[3]</sup>. Therefore, it is not surprising that a vast body of research on a range of prostate cancer related issues is available. However, in almost all of the research conducted to examine issues affecting men with prostate cancer, an important factor that is often ignored is their sexual orientation\*. The absence of information about sexual orientation in cancer surveillance efforts<sup>[7]</sup> means that the experiences of gay and bisexual men<sup>†</sup> with cancer are poorly understood<sup>[8]</sup>.

## GAY AND BISEXUAL MEN WITH PROSTATE CANCER

There are no published research findings indicating that gay men are diagnosed with prostate cancer at a different rate when compared with heterosexual men<sup>[9]</sup>, which means prostate cancer is just as important as a health concern for gay and bisexual men as it is for heterosexual men. While the endeavour to identify the percentage of gay or bisexually identified individuals within a population can be challenging due to methodological and definitional issues<sup>[10,11]</sup>, using a very conservative estimate of 3-5% of the total male population as gay identified<sup>[12,13,14]</sup>, it can be assumed that of the 19,400 plus new prostate cancer diagnoses reported in 2009, between 600 to 1,000 gay and bisexual men will be diagnosed with prostate cancer, adding to the many more who are already living with the disease. This estimation could be even higher given

a recent survey conducted by PCFA, which explored the awareness and attitude of men aged between 18 and 50 pertaining to prostate cancer<sup>[15]</sup>, found that 7% of the total number of respondents identified as gay, 4% as bisexual, and a further 3% identified as non-heterosexual. This is a critical issue, for it has been argued that while the cancer will affect gay and bisexual men in the same way as heterosexual men, some of their concerns and lived experiences will be different<sup>[9,16]</sup>.

The extensive amount of prostate cancer psychosocial research has provided thoughtful and insightful understanding into the experiences of living with the disease from multiple perspectives, such as from the men themselves, their partners and as couples. For example, there has been research examining the knowledge and attitudes of men about prostate cancer<sup>[e.g. 17,18]</sup>, the effects of prostate cancer on men's psychological and emotional

---

\* Sexual orientation is defined as 'an enduring emotional, romantic, sexual, or affectional attraction toward others' and it 'exists along a continuum that ranges from exclusive heterosexuality to exclusive homosexuality and includes various forms of bisexuality'<sup>[6, p.656]</sup>.

† Notwithstanding that there are men who have sex with men or other homosexually active men but non-gay identified, men in heterosexual relationships but are sexually active with men, and transgender women, the issues presented might not fully reflect their needs and experiences in the context of prostate cancer. Their needs and issues require a separate examination.

# INTRODUCTION

(continued)

health<sup>[e.g. 19, 20]</sup>, their sense of masculinity<sup>[21]</sup>, their sexual and intimate relationships<sup>[e.g. 9, 22, 23, 24]</sup>, sexual rehabilitation after prostate cancer<sup>[e.g. 25, 26]</sup>, as well as the impact on their partners<sup>[e.g. 27, 28]</sup>. These issues examined are pertinent and reflect the needs of people affected by prostate cancer, but the focus is hetero-centric, and issues specific to gay and bisexual men are often neither acknowledged nor addressed.

While it could be argued that biomedical science research on prostate cancer can be conducted without needing to take into account the individual's sexual orientation, this cannot be the case when the research is about the psychosocial impact of prostate cancer as subjectively experienced and understood. Except for a very few examples<sup>[e.g. 9, 29, 30]</sup>, the recognition that prostate cancer affects gay men as well as heterosexual men is rarely made, for there appears to be the presumption that the sexual orientation of the man with prostate cancer is irrelevant.

In one study examining the sexual, psychological and relational experiences of couples affected by prostate cancer, gay men were specifically excluded, as it was argued that 'too few partnered homosexual men were seen in the urology outpatient clinic for effective analysis'<sup>[31, p.781]</sup>. This methodological decision reflects other entrenched problems experienced by all non-heterosexually identified individuals (e.g. gay men, lesbians, bisexual men and women) in health care contexts. For example, although it can be assumed gay and bisexual men have similar health concerns as heterosexual men<sup>[32]</sup>, the health care system is 'heterosexist and homophobic in the way that it is structured'<sup>[33, p.13]</sup>, such as by assuming that everyone is heterosexual in its administration, which has the effect of making all non-heterosexually identified individuals feel 'invisible or unwelcome'<sup>[34, p.73]</sup> and thus possibly discouraging them from disclosing their sexual orientation. Specific to cancer, Bowen and Boehmer<sup>[8]</sup> found cancer registry systems do not

routinely seek information about sexual orientation from people with cancer. Failure to collect this information obscures the unique health care and social needs of all non-heterosexually identified individuals such as gay and bisexual men, which in turn further entrenches their marginalisation<sup>[35]</sup>. In an environment where they feel unwelcomed, it is understandable that gay and bisexual men delay or forego contact with discretionary health services (e.g. cancer screening)<sup>[36]</sup>, or when they do, they are more likely to withhold personal information such as their sexual orientation and sexual practices for fear of stigmatisation, recrimination and discrimination<sup>[37]</sup>. This sense of exclusion may lead to gay and bisexual men not raising pertinent issues with health care providers, particularly in relation to sexuality. Consequently, the presence of gay and bisexual men is under-represented, which reinforces the methodological decision noted earlier, and in the process, further discounting the needs of gay and bisexual men in prostate cancer research. Moreover, on occasions when gay and bisexual men's health is being discussed in mainstream settings, their perspectives are unavailable due to the lack of research, and therefore evidence-based knowledge, to disrupt or contest dominant discourses<sup>[38]</sup>.

## RESEARCH ON GAY AND BISEXUAL MEN AND PROSTATE CANCER

There is only a small number of publications that have focussed on the personal experiences of gay and bisexual men in the context of prostate cancer, for example, Dowsett<sup>[39]</sup>. Badr and Carmack Taylor<sup>[40]</sup> indicated that the experiences of gay and bisexual men following prostate cancer diagnosis and treatment are under-researched. Little is known about gay male relationships where both partners are diagnosed with prostate cancer, and how male-to-male support is similar to or different from female-to-male support in the context of prostate cancer. With the exception of a recent exploratory study on changes to sexual relationship after treatment in three gay couples<sup>[41]</sup>, how prostate cancer

treatment affects sexual functioning and relationship issues could be different for gay and bisexual men compared with heterosexual men [e.g. 42, 43, 44] such as men in 'open' relationships [45] is under researched. With regards to sexual activities, the inability to ejaculate or produce semen after prostate cancer treatment can be a significant issue as study findings have indicated that semen exchange in an important act for some gay and bisexual men during sex [46, 47]. Moreover, no research has yet reported on the impact of treatment on anal sex and sexual pleasure after prostate surgery [48] even though it has been suggested that the insertive/active ('top') partner in anal sex requires a higher degree of erectile rigidity than for vaginal sex [16], or that the receptive/passive ('bottom') partner may be more concerned about adverse bowel and rectal effects than erectile function [49]. Of the very few research studies that included gay and bisexual men, one indicated that gay and bisexual men who had hormone therapy for prostate cancer were more affected psychosexually than their heterosexual counterparts [50]. Kleinmann et al. [49] found that a man's sexual orientation has significant effects on his quality of life subsequent to prostate cancer treatment, which supports the finding that gay men with prostate cancer are particularly vulnerable to a decrease in quality of life after treatment [51].

## PROSTATE CANCER INFORMATION FOR AUSTRALIAN GAY AND BISEXUAL MEN

The lack of information about gay and bisexual men's lived experiences with prostate cancer has made their social, sexual and information needs unclear. However, it can be construed from the limited

research findings available that their experiences and needs in relation to prostate cancer cannot be assumed to be the same as heterosexual men. It is therefore encouraging that there has been a call for health education to acknowledge that gay and bisexual men may experience health concerns differently from heterosexual men [32, 52]. Australian health policies [53, 54] have called on health service administrators and direct care providers to develop health promotion messages, information and services that are appropriate for gay and bisexual men, as well as to other non-heterosexually identified populations such as lesbians, bisexual women, transgender and intersex people. In this regard, it is unclear whether or not currently available information resources on prostate cancer cater to and are appropriate for gay and bisexual men, or if the information needs of Australian gay and bisexual men are identified and addressed.

The aim of this report is to examine the currently available information and promotion materials specifically for gay and bisexual men as well as issues these men deemed to be important pertaining to this health issue. To achieve this, two studies commissioned by Prostate Cancer Foundation of Australia (PCFA) and conducted by the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University are presented: 1) an audit of existing resources and websites providing prostate cancer information catering to the needs of gay and bisexual men ‡; and 2) key findings from a study that examined the prostate cancer health information resources and promotion needs for gay and bisexual men in Australia §. The results from these studies are presented in this report.

---

‡ Formal title: *Gay men and prostate cancer: Report on an audit of existing resources and websites providing information to men living with prostate cancer in Australia, 2011*. Authors: Duane Duncan, Jan Watson, Andrew Westle, Anne Mitchell and Gary W. Dowsett

§ Formal title: *'They just assume everyone's straight': A technical report on prostate cancer and health promotion for gay and bisexual men*. Authors: Gary W. Dowsett, Anne Mitchell and David O'Keeffe (commissioned as part of the *Supporting men with prostate cancer through evidence-based resources and support project*, a Cancer Australia initiative, funded by the Australian Government)

# STUDY I: AN AUDIT OF EXISTING RESOURCES AND WEBSITES PROVIDING INFORMATION TO GAY AND BISEXUAL MEN WITH PROSTATE CANCER

## INTRODUCTION

Health promotion and information resources are often designed for the general population without considering the unique needs, interests and concerns of specific population groups. While this expedient approach can be useful in some health promotion and information provision contexts, its effectiveness is limited when aiming to meet the needs of individuals for whom health information has to be presented in ways that are personally relevant and inclusive. This has led to the assertion that 'one size does not fit all' with respect to resource development<sup>[55]</sup>. Resources that are interpreted by individuals to be meeting their specific needs, catering to their circumstances, and respecting their life experiences are more likely to be regarded as relevant<sup>[56]</sup> and more effective<sup>[57, 58]</sup>. From this perspective, it has been argued that health information materials need to be appropriately expressed and framed in order to achieve the desired outcome<sup>[59]</sup> through the development of 'targeted generic materials' to reach specific population groups<sup>[55, p.276]</sup>.

It is from this perspective that an audit of existing printed and online materials providing prostate cancer care and information was conducted. This audit functioned to identify and assess existing general men's health, and prostate cancer materials and resources that meet the information and support needs of gay and bisexual men in relation to prostate cancer.

## METHODOLOGY

The audit was conducted during the period between June and November 2011. Effort was made to review a wide range of print and online materials and resources. While it is not possible to claim that every piece of information available to men with prostate cancer in Australia was reviewed for this audit, the review was representative of the range of resources and information available to gay and bisexual men.

The audit included:

- Print resources for men with prostate cancer and their carers
- National, State and Territory Cancer Council websites
- National and State government and non-government organisations providing health-related information to men on the internet
- A selection of International government and non-government organisations providing health-related information on the internet
- National and State government men's health policies/strategies
- National People Living with HIV/AIDS (PLHIV) organisation websites
- Material for health professionals on the management of prostate cancer.

The materials and resources identified were assessed with regard to whether they might: (a) reasonably be expected to provide information on sexuality issues to men diagnosed and treated for prostate cancer; and (b) reasonably be expected that the information provided address the specific concerns and issues of gay and bisexual men.

Although a number of materials were identified as offering appropriate information on prostate health (e.g. prostate cancer symptoms, policy and

research related to prostate cancer), some of them are unlikely to be accessed by men, regardless of sexual orientation, who are looking for information related to sexuality issues following diagnosis and treatment. However, these resources or websites might benefit from providing information regarding sexual and relational issues to all men, including gay and bisexual men. See Appendix for full details of materials and websites included in the audit.

## ASSESSING THE RESOURCES

Resources and websites likely to be viewed by men seeking information or advice relating to sexuality, relationships, and prostate cancer were assessed to determine if the information provided was inclusive of gay and bisexual men. Five variables were considered.

1. Are there references to partners (as opposed to wives and husbands) as carers and significant others in a way that gay men might see themselves as included in the information offered?
2. Are gay men specifically addressed as men who might experience prostate cancer?
3. Is there specific information provided that addresses gay men's relationships, sexual practices or identities?
4. Are there a variety of images including pictures of gay men?
5. Are there references or links to further information or support specifically for gay men and bisexual men?

In resources where neither heterosexual nor gay men were explicitly mentioned, they were assessed to determine if gay and bisexual men might see themselves included, or if the resources, explicitly or implicitly, assumed that all men were heterosexual.

# STUDY 1: AN AUDIT OF EXISTING RESOURCES AND WEBSITES PROVIDING INFORMATION TO GAY AND BISEXUAL MEN WITH PROSTATE CANCER (continued)

In resources where neutral language (e.g. partner) was used, or even where gay men were specifically mentioned, they were assessed to determine if the issues and concerns of gay and bisexual men were actually covered or were, in fact, invisible. For example, some resources used neutral language such as partner, and even addressed gay men, but only provided information on penile-vaginal sexual practices.

## OUTCOME OF AUDIT

Despite the availability of a large body of materials and resources relevant to men living with prostate cancer, the audit revealed that information specifically for and relevant to gay and bisexual men was scarce. The materials and resources reviewed, both printed and online formats, offered a large amount of information for those with cancer, their carers, partners and families, and health professionals but usually of a general nature.

The language and imagery (both pictorial and graphic) contained in online materials and resources generally assumed heterosexuality, with relationships overwhelmingly being depicted as between men and women. Even when the term 'partner' was used, it appeared to represent the experiences of men who were in a relationship with women. A significant example of the invisibility of gay and bisexual men and their needs is related to the topic of erectile dysfunction as a result of prostate cancer treatment. In all instances, this topic is discussed in the context of heterosexual sexual activity. Where men were advised to contact a support line associated with the organisation responsible for the resource or information being viewed, it was not clear that these services were trained to answer questions specific to gay and bisexual men's concerns and issues.

A variety of medical and allied health professionals may be involved in prostate cancer treatment and care. The evidence from this audit indicates a lack of acknowledgement of the specific needs of same-sex

couples, and gay and bisexual men in the diagnosis, treatment, management and care of prostate cancer. Prostate cancer health professionals need guidance in the form of professional training and resources to respond more effectively and sensitively to the needs of gay and bisexual men with prostate cancer as well as their partners, families, friends and support networks.

Where material is for health professionals on managing prostate cancer, there is no advice on working with gay and bisexual men or indication that not all their patients identify as heterosexual. This deficit is also reflected in men's health policies across Australia where there is no mention of issues related to gay, bisexual and other homosexually active men and prostate cancer.

At the time of the audit, HIV-specific and gay men's health organisations that provide resources and support to gay and bisexual men had no links to information on prostate cancer specifically targeting gay and bisexual men. The only exception being the AIDS Council of South Australia, which provided a link to *It's a real bugger isn't it dear?*, which is a resource for gay, lesbian, bisexual, transgender, intersex or queer people affected by cancer and contains one personal account of a gay man living with prostate cancer.

A number of websites were found to provide information specific for gay and bisexual men with prostate cancer. These are listed in Table 1, and may be of benefit in regard to revising the information and support information available to men with prostate cancer in Australia to better acknowledge differences in experience on the basis of sexual practice, relationships and identity.

**TABLE 1: WEBSITES SPECIFIC FOR GAY AND BISEXUAL MEN WITH PROSTATE CANCER**

<p>Health with pride, U.K. <a href="http://www.healthwithpride.nhs.uk/gay-mens-health/cancer/">http://www.healthwithpride.nhs.uk/gay-mens-health/cancer/</a></p>	<p>Health with Pride is an online resource for lesbian, gay and bisexual patients and the healthcare professionals who serve them. A specific resource addressing gay men and cancer (including prostate cancer) can be found at: <a href="http://www.healthwithpride.nhs.uk/uploads/files/172.Gay_Men_Cancer_Leaflet.pdf?phpMyAdmin=jwHkxTHdv7HOVBbzEsO1Y8Urn1">Http://www.healthwithpride.nhs.uk/uploads/files/172.Gay_Men_Cancer_Leaflet.pdf?phpMyAdmin=jwHkxTHdv7HOVBbzEsO1Y8Urn1</a></p>
<p>LGBT Cancer Program Social Network – Lesbian, Gay, Bisexual and Transgender Center, U.S. <a href="http://www.outwithcancer.com/">http://www.outwithcancer.com/</a></p>	<p>Out with Cancer is the world’s first program for Gay, Lesbian, Bi &amp; Transgender men and women diagnosed with cancer</p>
<p>National LGBT Cancer Project, U.S. <a href="http://www.lgbtcancer.org">http://www.lgbtcancer.org</a></p>	<p>LGBT cancer survivor community with strong advocacy focus</p>
<p>Malecare **, U.S. <a href="http://malecare.org/a-gay-mans-guide-to-prostate-cancer/">http://malecare.org/a-gay-mans-guide-to-prostate-cancer/</a></p>	<p>The world’s first and only non-profit organisation that supports and advocates for men who have sex with men and are diagnosed with cancer. Content is frequently updated for the gay and other homosexually active men cancer survivor community. The site also houses several online support groups: <a href="http://health.groups.yahoo.com/group/prostatecancerandgaymen/">http://health.groups.yahoo.com/group/prostatecancerandgaymen/</a></p> <p>Men can also visit and post on forum at <a href="http://malecare.org/forum/">http://malecare.org/forum/</a></p>
<p>LGBT Resources <a href="http://www.oncolink.org/resources/section.cfm?c=18&amp;s=61">http://www.oncolink.org/resources/section.cfm?c=18&amp;s=61</a></p>	<p>Information and support for LGBT people as they experience some unique challenges in cancer survivorship, including ‘coming out’ to providers and the effects of cancer on LGBT sexuality.</p>

\*\* Malecare is the largest prostate cancer support group and patient advocacy non-profit organisation in the US (www.malecare.org). PCFA is working in partnership with Malecare to develop prostate cancer information, resources and support for Australian gay and bisexual men.

# STUDY 2: AN EXAMINATION OF THE PROSTATE CANCER HEALTH INFORMATION RESOURCES AND PROMOTION NEEDS OF AUSTRALIAN GAY AND BISEXUAL MEN

## INTRODUCTION

There is a dearth of research into needs of gay and bisexual men in the context of prostate cancer. The lack of attention given to gay and bisexual men's experiences of prostate cancer has produced a situation where their information needs are obscured or assumed to be the same as those identified for heterosexual men. The outcomes from the audit (Study 1) indicated clearly that prostate cancer information resources and materials specifically for Australian gay and bisexual men are lacking and inadequate. In an attempt to redress this situation, this study aimed to examine the prostate cancer health information resources and promotion needs of Australian gay and bisexual men, and to provide an evidence base for PCFA on which to develop new health promotion resources targeting this population.

## STUDY DESIGN

This qualitative 'rapid assessment' study, using focus group discussions, collected information from gay and bisexual men about the health information resources and sources they sought, used and found helpful or not, when seeking answers to questions about their prostate health or cancer. Research ethics approval for the study was provided by the La Trobe University Faculty of Health Sciences Research Ethics Committee.

Participants recruited were men who self-identified as gay or bisexual, 40 years of age and over, and reported as having experienced prostate health issues, such as those: (1) with concerns about possible prostate cancer; (2) with a prostate cancer diagnosis awaiting eventual treatment; and (3) living with prostate cancer after diagnosis and treatment.

There were two prostate cancer support groups for gay and bisexual men (one in Melbourne and one in Sydney) established prior to this study as part of PCFA's initiative for gay and bisexual men. The coordinators of these groups were approached to invite group members to volunteer for this study. The two major gay men's health community agencies in Sydney (ACON, formerly the AIDS Council of NSW) and in Melbourne (Victorian AIDS Council/Gay Men's Health Centre) are partners in the PCFA initiative and also supported the promotion of this study. PCFA promoted the study through its various communication activities (website, support groups, newsletters) where appropriate. A range of other community organisations, groups, venues and services was also utilised in the promotion of the study. Additionally, paid advertisements were placed in the Sydney and Melbourne gay community media. No names or contact details were solicited from third party sources; only calls for volunteers were made asking them to contact the study staff at ARCSHS directly. Also, no names of participants have been used when reporting the findings.

## PARTICIPANTS

Six (6) focus groups were conducted with a total of 45 men. The age of the participants ranged

from 42 to 85. Approximately one third of the participants were recruited through the two aforementioned prostate cancer support groups for gay and bisexual men. The majority of participants self-identified as gay, and none self-identified as bisexual. However, some of the men had been in opposite-sex relationships and had children from these relationships. In terms of employment, 24 participants reported that they were working and 21 were retired. Four (4) participants identified as HIV-seropositive. The age, employment status, HIV status and any other identifiers were collected only if a participant had volunteered the information.

## DATA COLLECTION AND ANALYSIS

Data were collected through six focus group discussions conducted in Melbourne and Sydney. Notes were taken during the discussions and the sessions were also digitally audio-recorded and then transcribed and verified. Participants in the focus groups were informed of the purpose of the study, and that their participation was voluntary. They were also given information about the nature of the data collection and analysis before providing consent to participate.

The focus groups discussions were guided by the six key domains of inquiry. These domains were: (1) information support needs; (2) information needs on general prostate cancer health issues; (3) information on prostate cancer diagnosis; (4) information preferences (sources); (5) information on prostate cancer treatment; and (6) information availability.

Focus group transcripts and notes were subjected to descriptive and thematic analysis through repeated reviewing of transcripts to identify both shared and unique experiences, topics and suggestions. These materials were then reviewed by the study investigators and combined into themes across all the focus groups. The focus group discussion guide was altered as groups occurred in a process known as 'progressive focussing', which allows the researchers to reduce time spent on issues already clarified and pursue emerging or unexpected ones<sup>[60]</sup>.

# STUDY 2: AN EXAMINATION OF THE PROSTATE CANCER HEALTH INFORMATION RESOURCES AND PROMOTION NEEDS OF AUSTRALIAN GAY AND BISEXUAL MEN *(continued)*

## RESULTS

This section provides the four key themes drawn from the transcripts and notes of the focus group discussions. They are: (1) aspects of their experiences of prostate-related health issues; (2) their relationships with health care providers; (3) their ways of obtaining support; and (4) their search for resources pertinent to their needs as self-identifying gay men with prostate-related health issues.

### 1. EXPERIENCE OF PROSTATE-RELATED HEALTH ISSUES

All focus group participants expressed some concern about their prostate health. This was as a result of having a family history of the disease, a prostate-related health issue or prostate cancer itself.

Generally, the participants saw themselves as being quite well-informed about most health issues, especially on HIV and other sexually transmissible infections (STIs). However, at the start of each focus group discussion, a general question on awareness of prostate cancer was asked of the participants, and most of them reported knowing little about the prostate, other than those who had specific health issues with their prostates. In the main, most of the participants had limited knowledge of the prostate as an organ and its function.

*'Well, I knew very little about prostate cancer. I knew it was one of the more serious cancers to get. But I also thought it was a cancer that affected men older than myself. I was 46 when I was diagnosed. I thought it affected men in their 60s upwards, so I, I s'pose that was the big learning for me.'*

The fear they experienced relating to prostate cancer was often associated with their limited knowledge about the prostate and its function.

*'When I was diagnosed with prostate cancer, I was in shock. I knew nothing about it and had no one to turn to. Yeah, I just fell into a heap, and it was only through my GP [general practitioner] and by going online I found out stuff. But I was scared nonetheless.'*

Some of the participants had concerns about negotiating treatment options and if delaying surgery was a viable option.

*'Should I go in there and have it, have it blasted with, with radiotherapy? Should I have it cut out? Should I do this? Should I do that? And the longer they wait to make a decision, the more they are at risk. Most of us made a decision based on the information that was given to us at the time and that's what we finish up with.'*

A number of the participants spoke about their specific concerns about sexual function before and after treatment, and the degree to which this was a major concern for them.

*'Would it be fair to say that [when] prostate cancer rears its ugly head with the possibility of a guy not being able to get it up and, of course, that's really important.'*

For participants who were treated, some found the effect that treatment has had on their sexual function difficult to accept.

*'My libido practically disappeared straight away and that was a difficult thing to accept, especially when I had such an active sex life.'*

The changes in self-perception as a sexual being due to surgery and treatment were issues that distressed a number of participants.

*'I felt all at sea about how to explain the fact I couldn't get a hard-on with the guys I met at the sauna and these were guys I'd known for years.'*

In addition, the consequences of their inability to discuss this with their peers and to engage in a fulfilling sex life were sources of anxiety for a number of the participants.

*'Whether it be a myth or not, there's a lot of emphasis in the gay world as a single person in trying to meet other gay men via the net and so on that isn't that friendly at times. So there's a lot of I think pressure that you do need to be able to perform and you need to be able to perform well.'*

Others mentioned concerns about prostate health in relation to other health conditions. There would appear to be very little information on these issues and this is especially relevant to those who are HIV-seropositive.

*'For me, and I know this is definitely not the case for many people; my trip if you like with HIV and the tablets has been extremely painless. But for other people it can have all sorts of side effects, namely vomiting and diarrhoea, which I don't get.'*

For some participants who have lived with HIV as a life-threatening disease, it has given them a different perspective on living with prostate cancer and the treatment decision.

*'I would never presume to, to instruct someone about what they should do or not do with a diagnosis of prostate cancer. But, from my own situation in the last five or six years, I wouldn't have gone ahead with the, with the surgery if I'd known what I know now. And I probably feel I was being overly optimistic in terms of, you know, how much longevity I have, because HIV's gonna kill me before, way before the prostate cancer would have anyway. So at least I would have gone out in my, you know, fully intact.'*

Finally, there is one experience of prostate disease that is unique to gay men, which is that both partners can be diagnosed.

*'My first real knowledge of it was when my partner, who was the same age as [name] at the time, was diagnosed with prostate cancer 12 months before in fact I was diagnosed with prostate cancer. So my partner was diagnosed and had his prostate removed in March of 2010, and then I had mine removed in March 2011 because I was diagnosed with a level of cancer that I'd probably die with rather than from.'*

## 2. RELATIONSHIPS WITH MEDICAL CARE PROVIDERS

Most of the participants in the focus group discussions expressed concern about the nature of their relationships with health service providers, and this is a particular issue in dealings with urologists.

A major concern expressed pertains to the observation that 'they just assume everyone's straight'.

*'When I was at the urologist, he said to me, 'Oh, would you like your partner to come?' [I said] 'My partner's a male.' I thought he was gonna fall off the chair.'*

For some participants, to counter possible assumptions, they act assertively by disclosing their sexual orientation so their unique needs are met.

*'My urologist, the shock, he got a shock when I said I was a homosexual man. I asked him questions just straight out. I thought, 'Well, if he doesn't like it, tough titties', you know.'*

However, for others, the constant need disclose their sexual orientation in a medical context can be challenging.

*'It's around ... not having to come out again and not having to go through the, the finer details of what's your sexual history been like.'*

Despite the challenge, the outcome from being clear with health service providers about their sexual orientation is that their needs are likely to be met.

*'But what he's treating you [for], the way he's going to treat you is gonna impact on your sex life and your sexual ability. So that, I think it's crucial that he knows and understands where, where you're coming from.'*

Just as assumptions are made by health service providers about their patients with prostate cancer, assumptions are made about them by their patients as illustrated in the following accounts.

*'But, when I went to the actual urologist who was going to be doing the surgery, I didn't know what his attitudes were towards gay and bisexual men. I knew that there was a very lovely photograph of his wife and two children sitting on his desk. I wanted to ask some questions because I wanted to know if prostate cancer and the commonality of it is in some ways linked to gay men. I'd heard rumours that that might be the case. But because I didn't know his attitude, I approached with caution.'*

## STUDY 2: AN EXAMINATION OF THE PROSTATE CANCER HEALTH INFORMATION RESOURCES AND PROMOTION NEEDS OF AUSTRALIAN GAY AND BISEXUAL MEN *(continued)*

Similarly, another man spoke of his concerns about his urologist with respects to his urologist's receptiveness to issues pertaining to gay men with prostate cancer.

*'...a lot of those questions were in my mind but to say to my heterosexual urologist, who's a lovely man – I didn't know how receptive he'd be to answering those kinds of questions.'*

The assumptions made by health professionals and patients about each other produce a reticence on both parts and exacerbate existing communication problems in clinical settings, such as those relating to sexuality and sexual function subsequent to treatment.

*'Mine was a passing half-sentence of, 'Oh, you might be impotent afterwards', and then continued on with the conversation.'*

Furthermore, a number of participants thought that the role of the prostate and its impact on sexual function and enjoyment for gay men was not well understood by medical practitioners.

*'But one of the things that he didn't care from the point of view of gay men is that the prostate plays more, more of a role for a gay man than it does to a straight man.'*

The amount of medical consultation time available is an important issue. The amount of time participants sometimes had with the doctor for each consultation was not always adequate and the doctor could not always answer questions in sufficient detail.

*'And you, you know, you're there, you're worried, you're frightened. You, you, you've got the big word 'cancer' flashing up in your [mind], when, when you've been sitting out in the waiting room for half-an-hour and you've only got ten minutes with them, and they're throwing all these choices at you about this is your choice, this is what you've gotta do, this is what, what it'll cost, this is what it'll, you know. It's overwhelming.'*

Despite the dissatisfaction with the time available and not always receiving sufficient amount of information, a number of participants reported that their GPs were the key players in terms of obtaining information about prostate cancer, and the person from whom they sought information in the first instance.

*'The GP is the linchpin of and the gatekeeper of our health system ... So it seems to me that our, we need to have information for the GPs that they can access on a needs, as needs basis, because prostate cancer is competing with thousands of other cancers and other, and it's not about getting out there and educating the GPs to be proactive, 'cause it ain't gonna work, but we need to have information that the GPs can pull out and say, 'Look, here is stuff and I'll print this off for you – you can go away about it – and here are the resources', so that it's easy for them. And, if it's gonna be effective, that's really the way we've gotta move.'*

### 3. WAYS OF OBTAINING SUPPORT

The participants often described how they relied on formal and, more often, informal networks for support. Of those who had partners at time of diagnosis, most found they could be relied upon to help them through the treatment. For participants who were single, it was an isolating and fearful process during which the opportunity to have had more support would have been of great benefit. The participants generally thought that 'mentors', preferably other gay men with prostate cancer treatment experiences, would have been a very welcome source of such support.

*'He could be put in confidentially say with a guy who was, had it 10 years ago or something or other, and experienced it. Just, I found that very hard to get and I, I got in a support group in Sydney. I know there's a support group here [in Melbourne]. I don't know what it's like.'*

Having a partner or friend who could assist in visits to the doctor or trips to the hospital was seen as important.

*'If it's your partner or friend, sometimes just the friend is good because they, they're kind of like the, almost like an outsider and they'll sit there, and they'll ask these questions. And they almost like write down the answer. And go, 'Okay'. And then when you come out, say, like, 'What did he say'? And they'll say ... I've heard that a number of times. That's really quite, quite good.'*

The need for emotional support is further emphasised by the following account, which highlighted that while having accurate information about prostate cancer is necessary, the opportunity to talk with someone about the emotional sequelae is equally important.

*'At the time that I was diagnosed, [having a] social worker or a counsellor who could take me into a different room and talk to me about something what I was experiencing. So rather than just facts and figures being bombarded at me in that time, just be able to support me would have been very important, which is what my counsellor has ultimately done, done very well.'*

In this regard, the opportunity to join a prostate cancer support group for gay men was seen as beneficial. The opportunity to express their feelings about the disease and its effects on their sex lives was seen as important.

*'I like the idea of a support group for gay men to meet and talk about the problems associated with prostate cancer and the like, but it's not something I would necessarily go to every month. Perhaps I'd use it only when I had a problem or was feeling down.'*

The support group was also crucial in getting the support needed in coping with the challenges resulting from prostate cancer treatment. For one man, the assurance given by other support group members was important when adjusting to the changes.

*'You really need I think a good support group, guys who have done it and they can say, you know, 'Look, it really took me three or four months like, you know, to get a hard-on again, before the sensation came down there.'*

The composition of the support group is significant for the participants, for shared experience and understanding of issues particular to gay men (e.g. gay sex) enhanced the efficacy of the group.

*'It has to be for gay men, not gay and straight. The straights just don't get what it means to be a gay man and the importance of the prostate in a gay man's sex life.'*

#### 4. THE SEARCH FOR INFORMATION

Information on prostate health and cancer is important for the focus group participants. They identified a number of topics and concerns that are relevant to them and should be included in information materials and resources. For example, the 'age bracket' when a 'prostate exam' needs to be considered, the meaning of the prostate specific antigen (PSA) test, the Gleason score so they know 'when it's high or the score good when it's not', how to prepare for treatment such as information on 'exercises [they could do] before there's any suggestion of even an operation' to enhance 'post-op recovery', and side effects as detailed in the following accounts.

*'No one ever mentions that you lose an inch or more on your dick when you have the surgery. That's a scary prospect for most men, gay or straight.'*

Many of the participants complained about the lack of specific information, both print and non-print, for gay men and their sexual and relationship needs in the context of prostate cancer. The participants often mentioned that, when asking about sex and sexual function, their medical providers tended to gloss over the issue or provide them with reading materials that were aimed at heterosexual men and ignored their specific needs.

## STUDY 2: AN EXAMINATION OF THE PROSTATE CANCER HEALTH INFORMATION RESOURCES AND PROMOTION NEEDS OF AUSTRALIAN GAY AND BISEXUAL MEN *(continued)*

*'I think I'd agree with that, but probably taking it one step further, a bit more specific about how and any subsequent treatment might affect someone's sexual interest, performance, enjoyment. Whether that person is classified as versatile or active, or passive – whatever the terminology you want in there. So what are the very specific interpretations for this, for gay men, and then also, if it does advance to having surgery, discuss what are the sort of risk factors and, and what do we know about it.'*

It was through searching on the internet and finding overseas-based websites or getting in contact with support groups that many of the participants received answers to the questions they required about sex and sexual function. One of the participants had this to say about access to information here in Australia.

*'We contacted friends in the United States and we actually got more information from the friends in the United States than we were able to get through people here, from a gay support group, because there was nothing. So we, actually almost [relied on] word of mouth and then books. They actually posted over or arranged to send over for us.'*

Many participants thought that there is currently a lack of resources that are specifically designed for gay men, and most participants thought this was a glaring omission.

*'So again, the same about a whole range of health, health and wellbeing issues: there needs to be a pictorial there of same-sex couples. And moves through the language are correct. There needs to be this specific information about how to, what the, what the issues potentially are and how to manage them in terms of gay men.'*

There were a few participants who said that the language in the resources for patients needs to be clear and concise, preferably in everyday language.

*'When we read the pamphlets they need to be in clear language, yeah, in the language any ordinary bloke can understand, not in something a university graduate or doctor has written.'*

Most of the participants indicated that there needs to be information on diagnosis written specifically for gay men so their experiences and needs are considered in the information.

*'I was having a discussion last night with my housemates. Why would we need something that's more tailored to gay men? And I said, 'Well, for any particular gay man looking for information, they wanna see themselves represented in the literature and the information, not only just images but also the language that people use in their writing'. I'm more likely to pick up something that identifies me in the material [rather] than something that just says, 'For all men, regardless of their sexual orientation, this is what you should be looking for'. Because it's just, it just is too general for me. I wanna know: there's something peculiar about my sexual behaviour, my sexual performance, pre- or post-treatment, whatever that treatment's about or whatever the diagnosis is about, what is it that makes us a little bit different? Is there anything different that we should be more mindful, as you said, about? And that's what I'm looking for.'*

Most of the participants thought that there is a role for gay men in helping write the resources. They said such a task requires gay men who understand both the relational, physiological and psychological needs of this group.

*'We also need gay men to write some of the stuff that relates to them. Who needs a married mum with four kids telling a gay man about anal sex? I mean, at least ensure that the information is road-tested with gay men before you put it out there.'*

Adding to the challenge of having to accept changes to their sexual function was the lack of information about these changes and what they need to do to recover, and in a manner that is relevant to them as gay men.

*'After my surgery, I wanted information that told me how long it would take to get an erection, how long before I could have anal intercourse and what things I needed to do to get better, but there was nothing for me as a gay man anyway.'*

Although the medical service provider was the first source of information on prostate health issues, the internet was a major source for information due to its accessibility and convenience. However, participants were aware that information obtained needed to be from a credible source.

*'I prefer to get my information online. I work full-time and I don't necessarily want to be running all over town trying to find a pamphlet with the information I need. I use the internet quite a lot, both at work and at home. I also met guys online, but that's another story. I mean what needs to be in place, as I'm sure you know is a website that has all the stuff, info gay men need about prostate cancer. And it needs to be controlled or endorsed by the Prostate Cancer Council or someone like them.'*

The needs of gay men in rural and remote communities were a concern participants thought could be addressed by appropriate online information, or by online or telephone mentoring.

*'When I lived in the bush I had no one to turn to. The town was quite a small, conservative place and heaven forbid anyone was gay. So I had to travel all the way to Sydney whenever I needed support from my gay friends. It was very isolating living in the bush.'*

While many of the participants expressed a preference for the internet, this related strongly to the age of the men. Most participants who were 75 years or older preferred information in a print format as illustrated in the following account.

*'As an older man, I don't know how to use a computer but I still want to know how prostate cancer will affect me. I much prefer to have a brochure with all the details to take home and read.'*

Participants argued that gay-specific pamphlets and booklets should be routinely provided at various health services and also at places and venues that gay and bisexual men frequent such as sex-on-premises venues, gay bars and pubs.

*'I need to be able to read things beforehand, so that I know what to go and ask him. And I used to work at [gay venue] behind the counter and I read all the brochures. They had some great brochures, which were provided by the VAC [Victorian AIDS Council/Gay Men's Health Service]. I read all of 'em. I'm a brochure reader. I'm, I'm that sort of person. And I would like to be armed with, oh shit, I've got four of these six symptoms, time to go and talk to my doctor about it. 'Cause he's not gonna find it otherwise unless I go and say, 'Look, I've got four of these six symptoms.'*

Several of the participants said that there is a role for AIDS Councils, gay men's health services, and organisations for people living with HIV to play in encouraging gay and bisexual men to take greater interest in general health issues, including prostate cancer.

*'A feeling that organisations such as VAC/GMHC, PLWHA Victoria [People living with HIV, Victoria], MSHS [Melbourne Sexual Health Service] and like organisations should play a bigger role in encouraging gay/bisexual men to take care of their general health needs, including issues such as prostate cancer.'*

The relevance of these organisations in addressing general health issues is that they are experienced in meeting the needs of gay men, for they are likely to be staffed by people to whom participants could relate.

*'I think the Gay Men's Community Health Centre [VAC/GMHC] ... But I don't wanna be, if I had prostate cancer, I don't wanna be talking to, to, you know, a 45-year-old mother of three. I want to have somebody that, that I can relate to as, as a gay man and that I can talk to about sexual practices without them getting embarrassed.'*

# DISCUSSION

The aim of this report is to examine the information needs of Australian gay and bisexual men relating to prostate cancer health. The findings from two studies commissioned by PCFA were used to achieve this aim. One study was an audit assessing the utility and appropriateness of currently available information materials on prostate cancer health for this population group, and the other study involved focus group discussions to identify their information needs pertaining to this important health issue.

## APPROPRIATENESS OF PROSTATE CANCER MATERIALS FOR GAY AND BISEXUAL MEN

The findings from the audit indicated that there is a large amount of information material on prostate cancer health available in both printed and online formats. Notwithstanding the usefulness of these materials in providing much needed information to people affected by cancer, they were assessed not to have addressed the specific needs of gay and bisexual men. With the exception of a few overseas websites (e.g. Malecare - USA, American Cancer Society - USA) and one South Australian publication ('It's a real bugger isn't it dear?'), most of the materials audited were deemed to be inadequate or had ignored the needs of gay and bisexual men. In terms of visual representation, images used in materials assessed often reflect heterosexuality, and clear images of gay and bisexual men were largely absent. The poor representation of gay and bisexual men in both content and images identified in the audit findings perpetuates the need for them to 'read' themselves into the materials in order to produce relevance, a marginalising practice that implicitly reinforces heterosexuality as the norm<sup>[61]</sup>. These findings were reflected by one focus group participant who reported that he had to contact friends overseas 'because there was nothing' he could find to meet his information needs. The

lack of information can contribute to treatment regret when the chosen treatment did not meet expectations<sup>[62]</sup> or treatment-related side effects were profound and unanticipated such as those relating to sexual functioning and sexuality<sup>[63]</sup>.

It is of interest to note that for many participants in the focus groups, despite the variety of ways through which information can be obtained as demonstrated by the materials assessed in the audit, their primary health professionals are often their main sources of information. While some participants reported that they had positive experiences with these health professionals, others found the assumptions that were made about them (e.g. being heterosexual) inhibited them from asking for information they required. The perceived discomfort of health professionals, and assumptions made (e.g. unreceptiveness) by some participants produced a situation where medical consultations were 'approached with caution' and uncertain if particular questions or issues could be asked or raised. This is consistent with research findings that showed assumptions about an individual's sexual orientation can produce unsatisfying medical encounters<sup>[38]</sup>, and can discourage the raising of issues pertinent to gay and bisexual men in the context of prostate cancer, and produce a reticence on both parts to discuss sensitive issues such as those relating to sexuality and sexual function after treatment.

## SPECIFIC INFORMATION NEEDS

Sexual function and sexuality issues ensuing from prostate cancer treatment were important concerns for participants in the focus groups, and many reported they were unable to locate relevant information that could 'speak' to them as gay and bisexual men. Notwithstanding the broad acknowledgement of, and attention given to, changes to sexuality and functioning following prostate cancer treatment<sup>[9, 64, 65, 66]</sup>, it is of concern that findings from the audit and focus group discussions suggest that these issues have largely been ignored from gay and bisexual men's standpoint. This is pertinent given 'the way many gay men view health and sexuality as being interlinked'<sup>[67, p.888]</sup>, particularly as a consequence of so many gay men living with and being affected by the HIV epidemic over the last 30 years.

Some gay and bisexual men are in relationships that are open or polyamorous<sup>[68]</sup> where there are different relationship rules<sup>[69]</sup>, and thus their relationship partners are not necessarily their exclusive sexual partners<sup>[70]</sup>. In this context, it is understandable that some participants highlighted the difficulties they anticipated, and experienced, in sexual encounters with both casual and regular sexual partners following prostate cancer treatment, and the impact these difficulties have had on their sense of self and social lives ('I felt all at sea about how to explain the fact that I couldn't get a hard-on'). These findings support previous research findings on sexual dysfunction following prostate cancer treatment where gay and bisexual men positioned

themselves as "damaged goods" incapable of future relationships'<sup>[62, p.527]</sup>. These distinctively gay and bisexual men's experiences are not covered in generic information materials.

The implication of these forms of relationships is that the generic information materials on prostate cancer relating to sexuality, sexual function and effects on relationships are unhelpful for gay and bisexual men, for they are centred on the needs of heterosexual men in long-term monogamous, mostly married relationships<sup>[42]</sup>. In this regard, there is a need for information materials to acknowledge that there are not only different forms of relationships but also different ways of negotiating sexuality issues arising from treatment that do not rest on the presumption that the individual has only one sexual partner or indeed, a partner. Although there are many gay and bisexual men in long-term relationships, there are many who are not<sup>[71]</sup>. A survey conducted by PCFA<sup>[15]</sup> showed that gay and bisexual men aged between 18 and 50 were more likely than their heterosexual counterparts to neither be in a relationship nor had been in a relationship. Findings from the focus group discussions indicate that being unpartnered and experiencing sexual dysfunction have implications on participants' social and sexual lives, for there is an 'emphasis in the gay world as a single person' being able to 'perform' sexually. This means the needs of unpartnered men with prostate cancer require specific attention and consideration also with respect to the production of information and support materials<sup>[72]</sup>.

## DISCUSSION

(continued)

### INFORMATION MATERIALS FOR GAY AND BISEXUAL MEN

While it can be argued that much of prostate cancer health information available is relevant to all men, obscuring and, hence, diminishing the needs of gay and bisexual men by producing only generic versions cannot be regarded as an equalising practice. The universalising of men's health information disempowers gay and bisexual men by discounting their unique needs and experiences<sup>[73]</sup>. This discounting practice is most apparent in the way that relationships are covered in generic information materials. Despite the recognition that prostate cancer is more likely to be experienced by men in same-sex relationships than men in heterosexual relationships due to the possibility of one or both partners being diagnosed with the disease<sup>[43, 68]</sup>, this is not reflected in the information materials. When ways of managing relationships are acknowledged and explained, the premise is about only one partner being diagnosed with the disease, and the other partner being the one who will provide support and care without considering that they might be diagnosed with it as well. This privileges a hetero-centric position, and side-lines information and issues that gay and bisexual men would require or find more pertinent, such as ways of coping when both partners have prostate cancer, and how to provide mutual support when both partners are experiencing treatment side effects.

The findings from the two studies are important, for they expose a troubling level of neglect of gay and bisexual men's specific needs relating to a health issue, which such men will need to consider, if not likely to confront, at some stage of their lives. Currently available prostate cancer information materials are not serving gay and bisexual men well,

for information is not presented in a manner that is relevant. It has been found that unless resources are interpreted by individuals to be personally relevant, they are unlikely to be effective<sup>[57]</sup>, and cultural appropriateness is central to relevance and to the success of health promotion communications<sup>[74]</sup>. In this regard, it is no longer appropriate to produce information materials on prostate cancer under the premise of 'one size fits all' if increased attention to health information is the desired outcome<sup>[75]</sup>. This lends support to the argument that while not every piece of health information needs to be developed and catered to gay and bisexual men, some health information, such as those pertaining to prostate cancer and the specific effects it has on their lived experiences, demands a gay-specific focus where a general focus has proved to be inadequate<sup>[67]</sup>.

The process of bringing gay and bisexual men's needs into focus in the prostate cancer domain requires structural and administrative changes within the health system, which include diversity training for health care professionals. It is no longer appropriate to discount sexual orientation as part of the data-gathering procedure in cancer registries, for this practice both perpetuates heterosexist assumptions and dismisses sexual diversity. Consequently, the experiences of non-heterosexually identified individuals are overlooked in cancer discourses, and therefore, their needs might continue to be ineffectually considered.

## MEETING THE NEEDS OF GAY AND BISEXUAL MEN

PCFA, being a broad-based organisation and the peak body for prostate cancer in Australia, is playing a proactive role in amending the situation identified in the reported findings regarding the unmet needs of Australian gay and bisexual men in prostate cancer information. Through its Gay and Bisexual Men's Prostate Cancer Initiative, with membership including leading health professionals, social scientists, researchers, educators, activists and policy makers experienced in gay and bisexual men's health as well as prostate cancer, PCFA has established clear strategic directions in its endeavour to provide appropriate and effective support to gay and bisexual men with prostate cancer. In partnership with Malecare, and through consulting and working closely with members of the gay and bisexual men community around the country, PCFA has established support groups specifically for gay and bisexual men in five capital cities (Adelaide, Brisbane, Melbourne, Perth and Sydney). The target is for PCFA to establish at least one such support group in all Australian capital cities, and in time, in regional areas with identified needs.

Specific to prostate cancer information materials, the Cancer Australia initiative, which enabled PCFA to commission ARCSHS to conduct one of the two studies reported on here, has also provided funding to develop a set of resources targeting gay and bisexual men with prostate cancer. Drawing on studies' findings and in consultation with members

of the target group, the resources 'speak' directly to gay and bisexual men by using appropriate images and plain non-medical language to inform gay and bisexual men of the diagnosis process, potential impacts of prostate cancer and its treatment on their social and sexual lives, as well as support and wellbeing issues following diagnosis and treatment. Issues that are significant and pertinent to gay and bisexual men are acknowledged and clarified in these resources so that they will be better informed when confronted by prostate cancer and its treatment. The issues covered include the prostate as a site of pleasure for gay and bisexual men during sex, the need for firmer erections in anal sex, change in penis size and orgasm resulting from treatment, the greater chance of gay and bisexual men in same-sex relationships facing prostate cancer, and ways to manage prejudice and discrimination that gay and bisexual men encounter in medical settings.

PCFA's endeavour to establish support groups for gay and bisexual men with prostate cancer, and the development of new resources serve to bring this group of men from the margin and into mainstream prostate cancer discourse. The illumination of their needs and issues through specific support groups and resources will address the concerns of this 'hidden population' by not only directly challenging the hetero-centric approach to prostate cancer information and care, but also ensuring that this population of men has specific and appropriate information to draw on when faced with a life-changing health concern.

# REFERENCES

1. Jemal, A., Bray, F., Center, M. M., Ferlay, J., Ward, E., & Forman, D. (2011). Global cancer statistics. *CA: A Cancer Journal for Clinicians*, 61(2), 69-90. doi: 10.3322/caac.20107
2. Yu, X. Q., Smith, D. P., Clements, M. S., Patel, M. I., McHugh, B., & O'Connell, D. L. (2011). Projecting prevalence by stage of care for prostate cancer and estimating future health service needs: protocol for a modelling study. *BMJ Open*, 1(1). doi: 10.1136/bmjopen-2011-000104
3. Australian Institute of Health and Welfare. (2012). *Cancer incidence projections: Australia, 2011 to 2020*. Canberra: AIHW.
4. Australian Institute of Health and Welfare. (2013). *The health of Australia's males: 25 years and over*. Canberra: AIHW.
5. Australian Institute of Health and Welfare. (2012). *Cancer in Australia: an overview, 2012*. Canberra: AIHW.
6. Dibble, S. L., Eliason, M. J., & Christiansen, M. A. D. (2007). Chronic illness care for lesbian, gay, & bisexual individuals. *Nursing Clinics of North America*, 42(4), 655-674.
7. Boehmer, U., Miao, X., & Ozonoff, A. (2011). Cancer survivorship and sexual orientation. *Cancer*, 117(16), 3796-3804. doi: 10.1002/cncr.25950
8. Bowen, D., & Boehmer, U. (2007). The lack of cancer surveillance data on sexual minorities and strategies for change. *Cancer Causes and Control*, 18(4), 343-349.
9. Latini, D. M., Hart, S. L., Coon, D. W., & Knight, S. J. (2009). Sexual rehabilitation after localized prostate cancer: current interventions and future directions. *Cancer Journal*, 15(1), 34-40. doi: 10.1097/PPO.0b013e31819765ef
10. Smith, A. M. A., Rissel, C. E., Richters, J., Grulich, A. E., & de Visser, R. O. (2003). Sex in Australia: sexual identity, sexual attraction and sexual experience among a representative sample of adults. *Australian and New Zealand Journal of Public Health*, 27(2), 138-145. doi: 10.1111/j.1467-842X.2003.tb00801.x
11. Dean, L., Meyer, I. H., Robinson, K., Sell, R. L., Sember, R., Silenzio, V. M. B., et al. (2000). Lesbian, gay, bisexual, and transgender health: findings and concerns. *Journal of the Gay and Lesbian Medical Association*, 4(3), 102-151.
12. Susman, E. (2011). Gay men face extra burden coping with prostatectomy. *Oncology Times*, 33(11), 23, 28-30.
13. Orsi, A. J. (2006). Exploring prostate cancer among gay men. *Communicating Nursing Research*, 39, 401-401.
14. Black, D., Gates, G., Sanders, S., & Taylor, L. (2000). Demographics of the gay and lesbian population in the United States: Evidence from available systematic data sources. *Demography*, 37(2), 139-154. doi: 10.2307/2648117
15. Lowe, A., Wong, T., & Lowe, S. (2013). *Prostate Cancer: the Next Generation - 2013 Community Attitude Survey*. Sydney: Prostate Cancer Foundation of Australia.
16. Cornell, D. (2005). A gay urologist's changing views on prostate cancer. In G. Perlman & J. Drescher (Eds.), *A gay man's guide to prostate cancer* (pp. 29-41). New York: Haworth Medical Press.
17. Arnold-Reed, D. E., Hince, D. A., Bulsara, M. K., Ngo, H., Eaton, M., Wright, A. R., et al. (2008). Knowledge and attitudes of men about prostate cancer. *Medical Journal of Australia*, 189(6), 312-314.
18. Lowe, A., Bennett, M., & Badenoch, S. (2012). *Research, awareness, support: ten years of progress in prostate cancer - 2012 Community Attitude Survey*. Sydney: Prostate Cancer Foundation of Australia.
19. Hedestig, O., Sandman, P.-O., Tomic, R., & Widmark, A. (2005). Living after radical prostatectomy for localized prostate cancer. A qualitative analysis of patient narratives. *Acta Oncologica*, 44(7), 679-686. doi: 10.1080/02841860500326000
20. Couper, J. W., Love, A. W., Dunbai, J. V., Duchesne, G. M., Bloch, S., Costello, A. J., et al. (2009). The psychological aftermath of prostate cancer treatment choices: A comparison of depression, anxiety and quality of life outcomes over the 12 months following diagnosis. *Medical Journal of Australia*, 190(7), S86-S89.
21. Oliffe, J. (2005). Constructions of masculinity following prostatectomy-induced impotence. *Social Science & Medicine*, 60(10), 2249-2259.
22. Beck, A. M., Robinson, J. W., & Carlson, L. E. (2009). Sexual intimacy in heterosexual couples after prostate cancer treatment: What we know and what we still need to learn. *Urologic Oncology: Seminars and Original Investigations*, 27(2), 137-143.
23. Couper, J. W., Bloch, S., Love, A., Duchesne, G., Macvean, M., & Kissane, D. W. (2006). The psychosocial impact of prostate cancer on patients and their partners. *Medical Journal of Australia*, 185(8), 428-432.
24. Couper, J. W. (2007). The effects of prostate cancer on intimate relationships. *The Journal of Men's Health & Gender*, 4(3), 226-232.

25. Chambers, S. K., Pinnock, C., Lepore, S. J., Hughes, S., & O'Connell, D. L. (2011). A systematic review of psychosocial interventions for men with prostate cancer and their partners. *Patient Education and Counseling*, 85(2), e75-e88. doi: 10.1016/j.pec.2011.01.027
26. Canada, A. L., Neese, L. E., Sui, D., & Schover, L. R. (2005). Pilot intervention to enhance sexual rehabilitation for couples after treatment for localized prostate carcinoma. *Cancer*, 104(12), 2689-2700.
27. Couper, J. W., Bloch, S., Love, A., Macvean, M., Duchesne, G. M., & Kissane, D. (2006). Psychosocial adjustment of female partners of men with prostate cancer: a review of the literature. *Psycho-Oncology*, 15(11), 937-953.
28. Manne, S., Babb, J., Pinover, W., Horwitz, E., & Ebbert, J. (2004). Psychoeducational group intervention for wives of men with prostate cancer. *Psycho-Oncology*, 13(1), 37-46.
29. Galbraith, M. E., Fink, R., & Wilkins, G. G. (2011). Couples surviving prostate cancer: challenges in their lives and relationships. *Seminars in Oncology Nursing*, 27(4), 300-308. doi: 10.1016/j.soncn.2011.07.008
30. Fergus, K. D., Gray, R. E., & Fitch, M. I. (2002). Sexual dysfunction and the preservation of manhood: experiences of men with prostate cancer. *Journal of Health Psychology*, 7(3), 303-316. doi: 10.1177/1359105302007003223
31. Soloway, C. T., Soloway, M. S., Kim, S. S., & Kava, B. R. (2005). Sexual, psychological and dyadic qualities of the prostate cancer 'couple'. *BJU International*, 95(6), 780-785. doi: 10.1111/j.1464-410X.2005.05400.x
32. Filiault, S. M., Drummond, M. J., & Riggs, D. W. (2009). Speaking out on GBT men's health: a critique of the Australian Government's Men's Health Policy. *Journal of Men's Health*, 6(3), 158-161. doi: 10.1016/j.jomh.2009.04.005
33. Blank, T. O., Asencio, M., Descartes, L., & Griggs, J. (2009). Aging, health, and GLBTQ family and community life. *Journal of GLBT Family Studies*, 5(1-2), 9-34. doi: 10.1080/15504280802595238
34. Irwin, L. (2007). Homophobia and heterosexism: implications for nursing and nursing practice. *Australian Journal of Advanced Nursing*, 25(1), 70-76.
35. Herek, G. M., Chopp, R., & Strohl, D. (2007). Sexual stigma: putting sexual minority health issues in context. In I. Meyer & M. Northridge (Eds.), *The health of sexual minorities* (pp. 171-208): Springer US.
36. Heslin, K. C., Gore, J. L., King, W. D., & Fox, S. A. (2008). Sexual orientation and testing for prostate and colorectal cancers among men in California. *Med Care*, 46(12), 1240-1248. doi: 10.1097/MLR.0b013e31817d697f
37. Semp, D. (2008). A public silence: the discursive construction of heteronormativity in public mental health services and the implications for clients. *Gay & Lesbian Issues and Psychology Review*, 4(2), 94-107.
38. Hinchliff, S., Gott, M., & Galena, E. (2005). 'I daresay I might find it embarrassing': general practitioners' perspectives on discussing sexual health issues with lesbian and gay patients. *Health & Social Care in the Community*, 13(4), 345-353. doi: 10.1111/j.1365-2524.2005.00566.x
39. Dowsett, G. W. (2008). "Losing my chestnut": one gay man's wrangle with prostate cancer. *Reproductive Health Matters*, 16(32), 145-150. doi: 10.1016/s0968-8080(08)32417-3
40. Badr, H., & Taylor, C. L. C. (2009). Sexual dysfunction and spousal communication in couples coping with prostate cancer. *Psycho-Oncology*, 18(7), 735-746.
41. Hartman, M.-E., Irvine, J., Currie, K. L., Ritvo, P., Trachtenberg, L., Louis, A., et al. (2013). Exploring gay couples' experience with sexual dysfunction after radical prostatectomy: a qualitative study. *Journal of Sex & Marital Therapy*, 1-21. doi: 10.1080/0092623x.2012.726697
42. Blank, T. O. (2005). Gay men and prostate cancer: invisible diversity. *Journal of Clinical Oncology*, 23(12), 2593-2596. doi: 10.1200/jco.2005.00.968
43. Santillo, V. M., & Lowe, F. C. (2005). Prostate cancer and the gay male. In G. Perlman & J. Drescher (Eds.), *A gay man's guide to prostate cancer* (pp. 9-27). New York: Haworth Medical Press.
44. Parkin, R. P., & Girven, H. (2005). Together with prostate cancer. In G. Perlman & J. Drescher (Eds.), *A gay man's guide to prostate cancer* (pp. 137-146). New York: Haworth Medical Press.

## REFERENCES

(continued)

45. Smith, J. A., Filiault, S. M., Drummond, M. J., & Knapman, R. J. (2007). The psychosocial impact of prostate cancer on patients and their partners. *Medical Journal of Australia*, 186(3), 159-160.
46. Holmes, D., & Warner, D. (2005). The anatomy of a forbidden desire: men, penetration and semen exchange. *Nursing Inquiry*, 12(1), 10-20. doi: 10.1111/j.1440-1800.2005.00252.x
47. Wassersug, R. J., Lyons, A., Duncan, D., Dowsett, G. W., & Pitts, M. (2013). Diagnostic and outcome differences between heterosexual and nonheterosexual men treated for prostate cancer. *Urology*, 82(3), 565-571. doi: 10.1016/j.urology.2013.04.022
48. Wittmann, D., Northouse, L., Foley, S., Gilbert, S., Wood, D. P., Jr., Balon, R., et al. (2009). The psychosocial aspects of sexual recovery after prostate cancer treatment. *International Journal of Impotence Research*, 21(2), 99-106.
49. Kleinmann, N., Zaorsky, N. G., Showalter, T. N., Gomella, L. G., Lallas, C. D., & Trabulsi, E. J. (2012). The effect of ethnicity and sexual preference on prostate-cancer-related quality of life. *Nature Reviews Urology*, 9(5), 258-265. doi: 10.1038/nrurol.2012.56
50. Motofei, I. G., Rowland, D. L., Popa, F., Kreienkamp, D., & Paunica, S. (2011). Preliminary study with bicalutamide in heterosexual and homosexual patients with prostate cancer: a possible implication of androgens in male homosexual arousal. *Bju International*, 108(1), 110-115. doi: DOI 10.1111/j.1464-410X.2010.09764.x
51. Hart, S., Coon, D., Kowalkowski, M., & Latini, D. (2011). Gay men with prostate cancer report significantly worse HRQoL than heterosexual men. *The Journal of Urology*, 185(4, Supplement), e68-e69. doi: 10.1016/j.juro.2011.02.231
52. Ferri, R. S. (2004). Issues in gay men's health. *Nursing Clinics of North America*, 39(2), 403-410. doi: 10.1016/j.cnur.2004.02.003
53. Commonwealth of Australia. (2010). *National male health policy - building on the strengths of Australian males*. Canberra: Department of Health and Ageing.
54. Commonwealth of Australia. (2012). *National lesbian, gay, bisexual, transgender and intersex (LGBTI) ageing and aged care strategy*. Canberra: Department of Health and Ageing.
55. Kreuter, M. W., Strecher, V. J., & Glassman, B. (1999). One size does not fit all: the case for tailoring print materials. *Annals of Behavioral Medicine*, 21(4), 276-283. doi: 10.1007/bf02895958
56. Kreuter, M. W., & Wray, R. J. (2003). Tailored and targeted health communication: strategies for enhancing information relevance. *American Journal of Health Behavior*, 27(Supplement 3), S227-S232.
57. Schmid, K. L., Rivers, S. E., Latimer, A. E., & Salovey, P. (2008). Targeting or tailoring? Maximizing resources to create effective health communications. *Marketing Health Services*, 28(1), 32-37.
58. Kreuter, M. W., Bull, F. C., Clark, E. M., & Oswald, D. L. (1999). Understanding how people process health information: a comparison of tailored and nontailored weight-loss materials. *Health Psychology*, 18(5), 487-494.
59. Myers, R. E. (2010). Promoting healthy behaviors: How do we get the message across? *International journal of nursing studies*, 47(4), 500-512.
60. Schutt, R. K. (2006). *Investigating the social world: the process and practice of research* (5th ed.). Thousand Oakes: Sage.
61. Johnson, C. (2002). Heteronormative citizenship and the politics of passing. *Sexualities*, 5(3), 317-336. doi: 10.1177/1363460702005003004
62. Thomas, C., Wootten, A., & Robinson, P. (2013). The experiences of gay and bisexual men diagnosed with prostate cancer: results from an online focus group. *European Journal of Cancer Care*, 22(4), 522-529. doi: 10.1111/ecc.12058
63. Parekh, A., Chen, M.-H., Hoffman, K. E., Choueiri, T. K., Hu, J. C., Bennett, C. L., et al. (2013). Reduced penile size and treatment regret in men with recurrent prostate cancer after surgery, radiotherapy plus androgen deprivation, or radiotherapy alone. *Urology*, 81(1), 130-135.
64. Dahn, J. R., Penedo, F. J., Gonzalez, J. S., Esquiabro, M., Antoni, M. H., Roos, B. A., et al. (2004). Sexual functioning and quality of life after prostate cancer treatment: considering sexual desire. *Urology*, 63(2), 273-277.

65. Chisholm, K. E., McCabe, M. P., Wootten, A. C., & Abbott, J.-A. M. (2012). Review: psychosocial interventions addressing sexual or relationship functioning in men with prostate cancer. *The Journal of Sexual Medicine*, 9(5), 1246-1260. doi: 10.1111/j.1743-6109.2012.02687.x
66. O'Brien, R., Rose, P., Campbell, C., Weller, D., Neal, R. D., Wilkinson, C., et al. (2011). "I wish I'd told them": A qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment. *Patient Education and Counseling*, 84(2), 200-207. doi: 10.1016/j.pec.2010.07.006
67. Adams, J., McCreanor, T., & Braun, V. (2013). Gay men's explanations of health and how to improve it. *Qualitative Health Research*, 23(7), 887-899. doi: 10.1177/1049732313484196
68. Filiault, S. M., Drummond, M. J. N., & Smith, J. A. (2008). Gay men and prostate cancer: voicing the concerns of a hidden population. *Journal of Men's Health*, 5(4), 327-332. doi: 10.1016/j.jomh.2008.08.005
69. Jowett, A., Peel, E., & Shaw, R. L. (2011). Sex and diabetes: a thematic analysis of gay and bisexual men's accounts. *Journal of Health Psychology*. doi: 10.1177/1359105311412838
70. Peplau, L. A., Veniegas, R. C., & Campbell, S. M. (1996). Gay and lesbian relationships. In R. C. Savin-Williams & K. M. Cohen (Eds.), *Lives of Lesbians, Gays, and Bisexuals* (pp. 250-273). Fort Worth: Harcourt Brace College Publishers.
71. McWhirter, D. P., & Mattison, A. M. (1984). *The male couple*. Englewood Cliffs: Prentice Hall.
72. Kazer, M., Harden, J., Burke, M., Sanda, M., Hardy, J., & Bailey, D. (2011). The experiences of unpartnered men with prostate cancer: a qualitative analysis. *Journal of Cancer Survivorship*, 5(2), 132-141. doi: 10.1007/s11764-010-0157-3
73. Adams, J., Braun, V., & McCreanor, T. (2007). Warning voices in a policy vacuum: professional accounts of gay men's health in Aotearoa New Zealand. *Social Policy Journal of New Zealand*, 30, 199-215.
74. Kreuter, M. W., Lukwago, S. N., Bucholtz, D. C., Clark, E. M., & Sanders-Thompson, V. (2003). Achieving cultural appropriateness in health promotion programs: targeted and tailored approaches. *Health Education & Behavior*, 30(2), 133-146.
75. Pedruzzi, R., Swinbourne, A., & Quirk, F. (2012). One size fits all: communicating the unknown in health promotion. *International Journal of Behavioral Medicine*, 19(Supp 1), S273-S274.



1  
**DIAGNOSING PROSTATE CANCER**  
Diagnosing prostate cancer

2  
**TREATING PROSTATE CANCER**  
Treating prostate cancer

3  
**MANAGING PROSTATE CANCER SIDE EFFECTS**  
Managing prostate cancer side effects in **EDY** and **LDY**

4  
**MAINTAINING WELLBEING**  
Maintaining wellbeing with prostate cancer and bilateral robot



Prostate Cancer  
Foundation of Australia

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50
---	---	---	---	---	---	---	---	---	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----

# APPENDIX: AUDIT OF PRINT AND ONLINE INFORMATION ABOUT PROSTATE CANCER (JUNE – NOVEMBER 2011)

## PRINT INFORMATION ABOUT PROSTATE CANCER

**A large body of print material on prostate cancer produced in Australia for the following audiences:**

- Patient
- Partner, families, friends, carers
- Health care professionals
- Social security policy makers and contact staff
- Members of gay men's support groups
- Members of prostate cancer support groups.

Note: Some resources and websites were identified as being unlikely to be accessed by men, regardless of sexual orientation, who are looking for information related to sexuality issues following diagnosis and treatment, such resources and websites are assessed as 'N/A' (not applicable).

Resource	Reference to partner (implied inclusion of gay and OHAM <sup>††</sup> )	General reference to gay and OHAM (inclusive language)	Specific reference to gay and OHAM (including issues such as relationships, gay sexuality, accessing supportive services)	Are there inclusive images of gay and OHAM?	Are there links to further information / resources / contacts specifically for gay and OHAM?	Notes/Recommendations
<b>A brief look at men's cancers</b> (n.d.) Cancer Council, Victoria – facts about prostate cancer	N/A	N/A	N/A	N/A	N/A	No changes recommended.
<b>Advanced prostate cancer a guide for men and their families (2009)</b> Cancer Council Australia	Yes.	Designed to be neutral (partner, care team), but gay and OHAM are invisible in the information.	No specific information addressed to gay men; side effects, impact of radiation; Section 9.3.7 – psychosocial support does not refer to specific support for gay men, support groups for gay men, and access... information.	N/A	Perلمان and Drescher (2005) appears in Ch.11 on partners and carers.	Additional information to meet the needs of gay and OHAM should be incorporated throughout the document, particularly in relation to the sections on families, partners and carers, hormone therapy and its side effects, sexual performance and body image, and psychosocial supports. More quotations reflecting the experience of gay and OHAM could be included. Friendships as care networks. Need to provide links to gay support groups, GLBT <sup>‡‡</sup> health agencies, etc.
<b>Caring for someone with cancer (2009)</b> Cancer Council New South Wales	Yes. 'Husband' on p.25 could be changed to partner.	Designed to be neutral. Gay and OHAM invisible.	No specific information addressed to gay and OHAM.	Cartoons. No.	No.	Provide links to specific information. Acknowledge gay and OHAM in section on Sexuality (p.31).

<sup>††</sup> OHAM – Other Homosexually Active Men

<sup>‡‡</sup> Gay, Lesbian, Bisexual, Transgender

<b>Continence and prostate a guide for men undergoing prostate surgery (2007)</b> Continence Foundation of Australia	N/A Generic health information.	N/A	N/A	No.	No.	No.	Perhaps include photo of gay couple with other pictures. Provide links to GLBT health agencies.
<b>Coping with a diagnosis of prostate cancer (n.d.)</b> Cancer Council of Queensland	Yes.	No.	No specific information addressed to issues of concern for gay and OHAM. No acknowledgment of possible differences between straight and gay and OHAM in regard to sexuality. In regard to sexuality, men also are assumed to be in relationships, not single.	20 images – 2 of gay couples.	Reference to Perlman and Drescher (2005).	More visibility in the text – explicitly acknowledge that gay and OHAM may have specific issues. Change ‘facing a divorce’ to ‘ending a relationship’. Provide links to GLBT health services and prostate cancer support groups for gay and OHAM.	
<b>Localised prostate cancer a guide for men and their families (2010)</b> Cancer Council Australia	Yes.	Designed to be neutral.	No specific information addressed to gay and OHAM – i.e. impact of radiotherapy on anal sexual practice.	No. One pictorial image of heterosexual couple (p.4).	No.	P.52 – problems in rectum could address gay men’s concerns and experiences. Add Perlman and Drescher (2005), and international websites to resources section.	
<b>Prostate cancer support: What every man should know (n.d.)</b> Prostate Cancer Foundation of Australia	Partners not mentioned.	No.	N/A	Single men and a heterosexual couple featured.	No.	Need to include support groups for gay and OHAM as they develop.	

<p><b>Prostate Health Improvement Program (Mr PHIP series) (2006)</b> Cancer Council South Australia</p>	<p>Yes.</p>	<p>No.</p>	<p>No specific information for gay men on effects of treatment on sexual function, sexual life, relationships, identity. Vaginal penetration is specifically addressed in section on sexual function. Assumes patient is heterosexual.</p>	<p>N/A (limited cartoons)</p>	<p>No.</p>	<p>Need to address gay men's sexual practice and implications of treatment for sexual function, relationships, identity, etc.</p>
<p><b>Sex after treatment prostate cancer (n.d.)</b> Cancer Council Queensland</p>	<p>Yes.</p>	<p>No.</p>	<p>Sexual orientation is mentioned as a factor that informs a man's understanding of sex. No other explicit reference to gay sexuality or relationships.</p>	<p>30 images – 2 of gay couples (one very young couple).</p>	<p>Yes, Perlman and Drescher (2005).</p>	<p>Incorporate quotes from gay men. Provide specific information on sex for gay and OHAM. Provide links to international gay and OHAM prostate cancer websites.</p>
<p><b>Sexuality, intimacy and cancer: a guide for people with cancer, their families and friends (2009)</b> Cancer Council New South Wales</p>	<p>Yes.</p>	<p>Yes.</p>	<p>Yes, a section on being in a same-sex relationship. Same-sex sexual practice is not covered. Sex outside of a relationship not addressed.</p>	<p>Graphics are of straight couples.</p>	<p>Yes, NSW GLBT health agency (ACON) is listed. Cancer Council Helpline is also suggested. ACON website also listed in resource list.</p>	<p>Question checklist – include specific questions for gay and OHAM to consider asking their doctor.</p>
<p><b>Sexuality and cancer: for people with cancer, their family and friends (2010)</b> Cancer Council Victoria</p>	<p>Yes.</p>	<p>Yes ('This booklet should be helpful whether you are...gay or straight...' (p.1).</p>	<p>Short on specific detail. No information pertaining to gay and OHAM or sex between men. No information regarding reduced penis size, rectal burning/scarring, depression, low testosterone, and ejaculation and orgasm changes specifically related to gay men. P.30 Potential problems of female partners but no corresponding section for male partners. P.39 Need for male partners to be acknowledged as carers.</p>	<p>Seven drawn images of heterosexual positions for intercourse. One photo of a heterosexual couple.</p>	<p>No.</p>	<p>Add an image of a gay couple. Provide a specific section addressing gay and OHAM sexuality and sexual practice. Identify specific questions gay and OHAM may wish to ask their treatment team. Acknowledge gay and OHAM's partners as carers and significant persons.</p>

<p><b>Maintaining your well-being: information on depression and anxiety for men with prostate cancer and their partners</b> (beyondblue in association with Prostate Cancer Foundation Australia) - a free booklet available from beyondblue <a href="http://www.beyondblue.org.au">http://www.beyondblue.org.au</a></p>	<p>Yes.</p>	<p>Cannot assume partners include gay men. No indication that gay and OHAM are included in the text.</p>	<p>No. No quotations from gay and OHAM or their partners, despite very many quotes from heterosexual couples. P.12 - 'Feeling like a man and having sex' - not specific acknowledgement of sexual identity or orientation in regard to sexual practice after prostate cancer.</p>	<p>11 photos - 2 of men alone, 1 of 2 men but not clear they are a couple. Heterosexual couple on the cover implicitly defines the booklet as for straight couples only.</p>	<p>Perlman and Drescher (2005) included. No GLBT health or support services advised.</p>	<p>Need to address effects of prostate cancer on gay and OHAM's relationships, sex lives, social activities, masculinity and body image. Include quotes from gay and OHAM, and their partners, throughout. Provide links to gay-friendly medical services (GP, psych, social workers etc.).</p>
---	-------------	--	---	--	--	---

# ONLINE RESOURCES: NATIONAL CANCER AND STATE CANCER COUNCIL WEBSITES

## National

Body/organisation & Website	Reference to partner (implied inclusion of gay and OHAM)	General reference to gay and OHAM (inclusive language)	Specific reference to gay and OHAM (including issues such as relationships, gay sexuality, accessing supportive services)	Are there inclusive images of gay and OHAM?	Are there links to further information / resources / contacts specifically for gay and OHAM?	Notes/Recommendations
<b>Cancer Australia</b> <a href="http://www.canceraustralia.gov.au/">http://www.canceraustralia.gov.au/</a>	No.	No.	No.	No images on the site.	Links to state based cancer councils and PCFA.	A policy website with a focus on women's cancers.
<b>Cancer Council Australia</b> <a href="http://www.cancer.org.au/home.htm">http://www.cancer.org.au/home.htm</a>	No.	No.	No. No references to sexual or relationship implications of prostate cancer in the information provided on this site.	No.	No.	More specific reference to sexuality and relationship issues could be made.

## State

Body/organisation & Website	Reference to partner (implied inclusion of gay and OHAM )	General reference to gay and OHAM (inclusive language)	Specific reference to gay and OHAM (including issues such as relationships, gay sexuality, accessing supportive services)	Are there inclusive images of gay and OHAM?	Are there links to further information / resources / contacts specifically for gay and OHAM?	Notes/Recommendations
<b>Cancer Council ACT</b> <a href="http://www.actcancer.org/">http://www.actcancer.org/</a>	Yes.	No.	No. Fact sheet link briefly mentions erectile problems after treatment.	No images of couples.	No.	More specific reference to sexuality and relationship issues could be made.
<b>Cancer Council NSW</b> <a href="http://www.cancercouncil.com.au">http://www.cancercouncil.com.au</a>	Yes.	No.	Link on front page to ThinkGP Cancer and Sexuality program.	No.	No.	The reading list could have a section for GLBT community.
Understanding prostate cancer <a href="http://www.cancercouncil.com.au/editorial.asp?pageid=85">http://www.cancercouncil.com.au/editorial.asp?pageid=85</a>	Reference to partner is made but hetero-sexuality is assumed.	No reference to gay and OHAM.	No reference to gay men or gay sexual relationships.	No images in publication.	No links specific for gay men and OHAM.	Address the sexual needs and behaviours of gay and OHAM in sexual health section. Inclusion of gay male anecdotes as well as the heterosexual examples would be helpful.
<b>Cancer Council Queensland</b> <a href="http://www.cancerqld.org.au/">http://www.cancerqld.org.au/</a>	Yes.	No.	No.	No.	No.	More specific reference to sexuality and relationship issues could be made.
<a href="http://www.cancerqld.org.au/page/information_resources/fact_sheets_and_statistics/">http://www.cancerqld.org.au/page/information_resources/fact_sheets_and_statistics/</a>	N/A	N/A	N/A	N/A	N/A	General fact sheet.

<a href="http://www.cancerqld.org.au/icms_docs/60389_The_Early_Detection_of_Prostate_Cancer_in_General_Practice_Supporting_Patient_Choice.pdf">http://www.cancerqld.org.au/icms_docs/60389_The_Early_Detection_of_Prostate_Cancer_in_General_Practice_Supporting_Patient_Choice.pdf</a>	A GP referral card – contains basic information about testing etc., no reference to any sexuality.	No.	No. There is no reference to the questions gay and OHAM might have regarding diagnosis.	No.	No.	No.	Insert a sentence stating that patients may not all be heterosexual. Acknowledge that sexuality will inform men's choices in treatment.
<b>Cancer Council SA</b> <a href="http://www.cancersa.org.au/asp/home.aspx">http://www.cancersa.org.au/asp/home.aspx</a>	Yes.	No.	No. Link to Mr Phip series (audited above). Section on Sexuality and cancer does not mention gay men.	No.	No. A broken link to AIDS Council of SA, via resource: 'Personal stories of different sexuality and cancer'.	No.	Specific acknowledgement of gay sexuality and links to supportive documents and services.
Sexuality for men with cancer <a href="http://www.cancersa.org.au/asp/Sexuality_for_men_with_cancer.aspx">http://www.cancersa.org.au/asp/Sexuality_for_men_with_cancer.aspx</a>	Partner is used but clearly means female partners.	Female is used in relationship to sex and cancer.	No mention is made of gay and OHAM's sexuality.	No.	No links to gay men's health services.	No.	Create a separate section that addresses gay and OHAM and their sexual practices.
Sexuality for men with cancer: A guide for men, their families and friends <a href="http://www.cancersa.org.au/resource_library/3/18/Sexuality_men_cancer_Oct2006.pdf">http://www.cancersa.org.au/resource_library/3/18/Sexuality_men_cancer_Oct2006.pdf</a>	Partner is used but refers to heterosexual relationships.	Reference is to heterosexual sex and penetration – no attempt to discuss gay and OHAM.	No reference made to gay and OHAM.	N/A	No links to gay men's health services.	No.	Written exclusively for heterosexual men, not all men. Need to provide a separate section to address gay sexuality.
<a href="http://www.cancersa.org.au/resource_library/3/16/Emotions_and_cancer_Dec2008.pdf">http://www.cancersa.org.au/resource_library/3/16/Emotions_and_cancer_Dec2008.pdf</a>	Yes.	No.	No. A section on sexuality does not identify different types of sexuality.	N/A	No.	No.	Insert a reference to indicate that cancer affects people differently depending on their sexuality.
<a href="http://www.cancersa.org.au/resource_library/3/17/About_chemotherapy.pdf">http://www.cancersa.org.au/resource_library/3/17/About_chemotherapy.pdf</a>	Yes.	No.	No. Effects of chemo on vagina and erection are discussed.	N/A	No.	No.	Address effect of chemo on broader aspects of men's sexual practices than erection.

<a href="http://www.cancersa.org.au/resource_library/3/17/Understanding_radiation_therapy.pdf">http://www.cancersa.org.au/resource_library/3/17/Understanding_radiation_therapy.pdf</a>	Yes.	No.	No.	N/A	No.	Address effect of radiation on broader aspects of men's sexual practices than erection.
<b>Cancer Council Tasmania</b> <a href="http://www.cancertas.org.au/">http://www.cancertas.org.au/</a>	Yes.	No.	No.	N/A	No. Not included in general health links.	Insert links to local GLBT health services.
<b>Cancer Council Victoria</b> Life after Cancer: A guide for cancer survivors <a href="http://www.cancervic.org.au/">http://www.cancervic.org.au/</a>	Partner used with a degree of inclusion.	Inclusion in the use of language without any specific references.	No.	N/A	No.	Include a specific reference to different experiences of GLBT populations, and guidance for further information.
<a href="http://www.cancervic.org.au/about-cancer/living-with-cancer/sexuality_and_cancer/potential_problems_men.html">http://www.cancervic.org.au/about-cancer/living-with-cancer/sexuality_and_cancer/potential_problems_men.html</a>	Partner is used.	No reference to gay men or sexual practice.	No information is given specifically for gay and OHAM.	N/A	No.	Specific reference to different sexual practices and relationships.
<b>Cancer Council WA</b> <a href="http://www.cancerwa.asn.au/">http://www.cancerwa.asn.au/</a>	Yes.	No.	No.	N/A	No.	Provide links to GLBT health services and acknowledge gay men in prostate cancer advice.

# NATIONAL AND STATE GOVERNMENT AND NON-GOVERNMENT ORGANISATION HEALTH-RELATED INFORMATION ON THE INTERNET

## Government

Body/organisation & Website	Reference to partner (implied inclusion of gay and OHAM )	General reference to gay and OHAM (inclusive language)	Specific reference to gay and OHAM (including issues such as relationships, gay sexuality, accessing supportive services)	Are there inclusive images of gay and OHAM?	Are there links to further information / resources / contacts specifically for gay and OHAM?	Notes/Recommendations
<b>Better Health Channel (Victorian Department of Health)</b> <a href="http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Prostate_gland_and_urinary_problems">http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Prostate_gland_and_urinary_problems</a>	N/A	N/A	N/A	N/A	No.	Generic description of prostate, cancer symptoms and treatment.
<a href="http://www.betterhealth.vic.gov.au/Bhcv2/bhcArticles.nsf/pages/Prostate_gland?openviQ_Cancer_Treatments_Online">http://www.betterhealth.vic.gov.au/Bhcv2/bhcArticles.nsf/pages/Prostate_gland?openviQ_Cancer_Treatments_Online</a>	N/A	N/A	N/A	N/A	No	Generic description of prostate, cancer symptoms and treatment.
<b>Australian Better Health Initiative</b> <a href="http://www.healthnetworks.health.wa.gov.au/abhi/home/">http://www.healthnetworks.health.wa.gov.au/abhi/home/</a>	Yes.	No.	No.	No.	Yes. Provides a search engine with links to documents of relevance to gay and OHAM and prostate cancer.	Website describing public health initiative to support good health practices and reduce burden of chronic disease.

## National and international networks and alliances

Body/organisation & Website	Reference to partner (implied inclusion of gay and OHAM )	General reference to gay and OHAM (inclusive language)	Specific reference to gay and OHAM (including issues such as relationships, gay sexuality, accessing supportive services)	Are there inclusive images of gay and OHAM?	Are there links to further information / resources / contacts specifically for gay and OHAM?	Notes/Recommendations
<b>Australian and New Zealand Urogenital and Prostate (ANZUP) Cancer Trials Group</b> <a href="http://www.anzup.org.au/">http://www.anzup.org.au/</a>	N/A	N/A	N/A	No.	No.	A Cancer Research Group website.
<b>Australian Canadian Prostate Cancer Research Alliance</b> <a href="http://www.aus-canprostatealliance.org/">http://www.aus-canprostatealliance.org/</a>	N/A	N/A	N/A	N/A	N/A	A prostate cancer research website.
<b>Australian Cancer Research Foundation</b> <a href="http://www.acrf.com.au/">http://www.acrf.com.au/</a>	N/A	N/A	N/A	N/A	N/A	A prostate cancer research website.
<b>The Australian Prostate Cancer Collaboration BioResource</b> <a href="http://www.apccbiorresource.org.au/">http://www.apccbiorresource.org.au/</a>	N/A	N/A	N/A	N/A	N/A	Cancer Charity Foundation Website.
<b>Cancer Forum (Cancer Council Australia &amp; Clinical Oncological Society of Australia official journal)</b> <a href="http://www.cancerforum.org.au/aboutcancerforum.html">http://www.cancerforum.org.au/aboutcancerforum.html</a>	N/A	N/A	N/A	N/A	N/A	Official journal of Cancer Council Australia and the Clinical Oncological Society of Australia (representing health professionals working in cancer).

## National and State organisations

Body/organisation & Website	Reference to partner (implied inclusion of gay and OHAM)	General reference to gay and OHAM (inclusive language)	Specific reference to gay and OHAM (including issues such as relationships, gay sexuality, accessing supportive services)	Are there inclusive images of gay and OHAM?	Are there links to further information /resources /contacts specifically for gay and OHAM?	Notes/Recommendations
<b>Andrology Australia</b> <a href="http://www.andrologyaustralia.org/pageContent.asp?pageCode=PROSTATEPROBLEMS">http://www.andrologyaustralia.org/pageContent.asp?pageCode=PROSTATEPROBLEMS</a>	Yes.	No.	No. Very little information on sexual and relationship implications of prostate cancer for men, gay or straight.	No.	No links to any gay men's health organisations.	Specific acknowledgement of gay sexuality and links to supportive documents and services.
<a href="http://www.andrologyaustralia.org/docs/Fact%20Sheet_ProstateDiagnosis_WEB.pdf">http://www.andrologyaustralia.org/docs/Fact%20Sheet_ProstateDiagnosis_WEB.pdf</a>	N/A	N/A	N/A	N/A	N/A	
<a href="http://www.andrologyaustralia.org/docs/Factsheet_Prostate%20Treatment_WEB.pdf">http://www.andrologyaustralia.org/docs/Factsheet_Prostate%20Treatment_WEB.pdf</a>	N/A	N/A	N/A	N/A	N/A	
<b>Australian Cancer Survivors Centre</b> - cancer survivorship advice for professionals and prostate cancer survivors <a href="http://www.petermac.org/Assets/1754/1/ACSC_FactSheet_PROFESSIONAL_FollowUpofProstateCancerSurvivors_REPRO.pdf">http://www.petermac.org/Assets/1754/1/ACSC_FactSheet_PROFESSIONAL_FollowUpofProstateCancerSurvivors_REPRO.pdf</a>	Partner is used with good effect.	Language where used is inclusive.	No reference to specific gay relationships or sexual practices.	Images of men alone or with doctor, no exclusion present.	No specific links for gay men.	Important to identify specific issues for gay and OHAM, and provide links to further information and support.

<b>Cancer Institute NSW</b> <a href="http://www.cancerinstitute.org.au/">http://www.cancerinstitute.org.au/</a>	Yes	No.	No. Very limited information in regard to prostate cancer.	N/A	No.	A specific section on sexuality and cancer that includes gay and OHAM would be useful.
<b>Continence Foundation Australia</b> - a nationally-funded advisory service <a href="http://www.continence.org.au">http://www.continence.org.au</a>	Yes.	No.	No.	No.	No.	Include references and links to GLBT health agencies.
<b>Healthinsite</b> - a <i>healthdirect</i> Australia health information service <a href="http://www.healthinsite.gov.au/topics/Prostate_Cancer">http://www.healthinsite.gov.au/topics/Prostate_Cancer</a>	N/A	N/A	N/A	N/A	The website is a collection of links to other websites. No links to gay men's resources.	This website could benefit from a grouping of resources and links for gay men.
<b>Lions Australia Prostate Cancer</b> (Australian Prostate Cancer Collaboration) <a href="http://www.prostatehealth.org.au/">http://www.prostatehealth.org.au/</a>	Yes.	Yes.	No specific references, but links to personal anecdotes and books.	N/A	Yes, Perlman and Drescher (2005).	
<b>Peter MacCallum Cancer Centre</b> <a href="http://www.petermac.org/UrologicalCancerInformation">http://www.petermac.org/UrologicalCancerInformation</a>	Yes.	No.	Links to a number of resources for men with prostate cancer. No specific information for gay and OHAM.	N/A	No.	Provide links to specific resources that address gay men's issues.
<b>Prostate Cancer Foundation of Australia</b> <a href="http://www.prostate.org.au/articleLive/">http://www.prostate.org.au/articleLive/</a>	Yes.	Used quite neutrally.	Support services are offered as well as press releases dealing with gay issues.	A few images of men together not obvious they are in a gay relationship.	Links to support groups for gay men and OHAM is the most obvious on the support page.	This website would benefit from a menu item that condenses some resources and services for gay men.

## Consumer sites

Body/organisation & Website	Reference to partner (implied inclusion of gay and OHAM )	General reference to gay and OHAM (inclusive language)	Specific reference to gay and OHAM (including issues such as relationships, gay sexuality, accessing supportive services)	Are there inclusive images of gay and OHAM?	Are there links to further information /resources /contacts specifically for gay and OHAM?	Notes/Recommendations
<b>Cancer Voices Australia</b> <a href="http://www.cancervoice.org.au/">http://www.cancervoice.org.au/</a>	Yes.	No.	No.	N/A	No.	An 'independent' voice for people affected by cancer.
<b>Prostate Cancer Support Group ACT</b> <a href="http://prostate-cancer-support-act.net/">http://prostate-cancer-support-act.net/</a>	Yes.	No.	Reference to anecdotes and personal stories all heterosexual.	No.	No.	A personal story from a gay or OHAM could be useful.

## National and State government Men's Health policies and other relevant strategies

Body/organisation & Website	Reference to partner (implied inclusion of gay and OHAM )	General reference to gay and OHAM (inclusive language)	Specific reference to gay and OHAM (including issues such as relationships, gay sexuality, accessing supportive services)	Are there inclusive images of gay and OHAM?	Are there links to further information /resources /contacts specifically for gay and OHAM?	Notes/Recommendations
<b>National Male Health Policy</b> <a href="http://www.health.gov.au/internet/main/publishing.nsf/Content/national%20mens%20health-1">http://www.health.gov.au/internet/main/publishing.nsf/Content/national%20mens%20health-1</a>	Yes.	Yes.	<p>No. Gay men are only addressed in the policy in regard to HIV/AIDS and other STIs (i.e. sexual risk). There is no specific consideration of prostate cancer and gay men.</p> <p>Gay and bisexual men are understood to be marginalised population groups with unique health needs, particularly in regard to depression and suicide (younger men).</p>	No specific images.	No.	

<p><b>Older Men's Health and Wellbeing</b> - a directory of links to organisations, services and resources  <a href="http://www.oldermenswellbeing.com.au/national1.html">http://www.oldermenswellbeing.com.au/national1.html</a></p>	No.	No.	No. Gay men are not mentioned; there are no links to specific GLBT organisations, services or resources. There are links to prostate cancer sites.	No images.	No.	
<p><b>Australian indigenous Health/Infonet</b> - Indigenous sexual health  <a href="http://www.healthinfonet.ecu.edu.au/other-health-conditions/sexual">http://www.healthinfonet.ecu.edu.au/other-health-conditions/sexual</a></p>	Yes.	Yes.	A website with links to health information for indigenous Australians. No specific links for gay men, or prostate cancer.	N/A	No.	
<p><b>New South Wales</b>  Men's Health Plan 2009-2012  <a href="http://www.health.nsw.gov.au/policies/pd/2009/PD2009_077.html">http://www.health.nsw.gov.au/policies/pd/2009/PD2009_077.html</a></p>	Yes.	Yes.	'Homosexual' men are briefly mentioned twice as a group of marginal men.	No.	N/A	
<p><b>New South Wales</b>  Aboriginal mental health and wellbeing policy 2006-10  <a href="http://www.health.nsw.gov.au/policies/pd/2007/PD2007_059.html">http://www.health.nsw.gov.au/policies/pd/2007/PD2007_059.html</a></p>	Yes.	No.	No mention of either gay men or prostate health in this document.	No.	N/A	
<p><b>South Australia</b>  South Australian Men's Health Strategic Framework 2008-2012  <a href="http://www.publications.sa.health.sa.gov.au/oppp/7/">http://www.publications.sa.health.sa.gov.au/oppp/7/</a></p>	Yes. 'Partners and significant others'.	No.	No. Prostate cancer is identified as a disease in need of more research funding only.	No images.	N/A	

<p><b>Victoria</b> Men's health and wellbeing strategy 2010-2014 <a href="http://www.livingwell.org.au/Portals/0/Living%20Well%20Files/PDFs/Victoria_mens_health_strategy.pdf">http://www.livingwell.org.au/Portals/0/Living%20Well%20Files/PDFs/Victoria_mens_health_strategy.pdf</a></p>	Yes.	Yes.	No. Gay men and prostate cancer are each well considered but not in relation to each other.	N/A	N/A	
<p><b>Western Australia</b> Aboriginal Men's Health and Well Being, a renewed focus <a href="http://www.aboriginal.health.wa.gov.au/docs/HP011000_Aboriginal_mens_health.pdf">http://www.aboriginal.health.wa.gov.au/docs/HP011000_Aboriginal_mens_health.pdf</a></p>	No.	No.	No. Neither prostate cancer nor gay men are addressed.	No.	No.	

# International government and non-government organisations providing prostate cancer information

Body/organisation & Website	Reference to partner (implied inclusion of gay and OHAM)	General reference to gay and OHAM (inclusive language)	Specific reference to gay and OHAM (including issues such as relationships, gay sexuality, accessing supportive services)	Are there inclusive images of gay and OHAM?	Are there links to further information/resources/contacts specifically for gay and OHAM?	Notes/Recommendations
<b>Prostate Cancer Canada</b> <a href="http://www.prostatecancer.ca/">http://www.prostatecancer.ca/</a>	Reference to loved ones.	Yes.	Reference to a pride march in their newsletter with photos.	N/A	Link to Perlman and Drescher (2005).	
<b>Vancouver Prostate Centre</b> <a href="http://www.prostatecentre.com/">http://www.prostatecentre.com/</a>	N/A	N/A	N/A	N/A	N/A	
<a href="http://www.cancerhelp.org.uk/type/prostate-cancer/">http://www.cancerhelp.org.uk/type/prostate-cancer/</a>	Very good use of partner/relationship.	Very inclusive.	No specific reference to issues faced by gay and OHAM.	N/A	Only general cancer links.	
<b>The Prostate Cancer Charity</b> <a href="http://www.prostate-cancer.org.uk/">http://www.prostate-cancer.org.uk/</a>	Yes.	Yes.	No specific reference to issues faced by gay and OHAM.	Images are neutral.	A link provided to GLBT Health Organisation.	
<a href="http://www.prostatecouples.com">www.prostatecouples.com</a>	Yes.	Yes.	Yes.	Yes.	N/A	A great resource that many websites and organisations could link to.

<b>UK Prostate Link</b> <a href="http://www.prostate-link.org.uk">http://www.prostate-link.org.uk</a>	Partner is used but heterosexuality is implied.	No.	No. References are specifically to heterosexual men.	No.	No.	No.
<b>American Cancer Society</b> <a href="http://www.cancer.org/">http://www.cancer.org/</a>	Reference is to heterosexual.	Reference in a few passing sentences in a PDF about sex.	In passing.	No.	One link in a PDF.	
<a href="http://www.cancer.org/Cancer/ProstateCancer/index">http://www.cancer.org/Cancer/ProstateCancer/index</a>	As above.	As above.	As above.	As above.	As above.	
<b>Cancer facts for gay and bisexual men</b> <a href="http://www.cancer.org/Healthy/FindCancerEarly/MensHealth/cancer-facts-for-gay-and-bisexual-men">http://www.cancer.org/Healthy/FindCancerEarly/MensHealth/cancer-facts-for-gay-and-bisexual-men</a>	Yes.	Yes.	Yes.	Yes.	Yes.	Specific information for gay and bisexual men on American Cancer Society website.
<b>Sexuality for the man with cancer</b> <a href="http://www.cancer.org/acs/groups/cid/documents/webcontent/002910-pdf.pdf">http://www.cancer.org/acs/groups/cid/documents/webcontent/002910-pdf.pdf</a>	Heterosexuality assumed.	No.	No. Two passing sentence in the 52 pages.	Images of heterosexual sex.	One link.	
<b>National Cancer Institute</b> <a href="http://www.cancer.gov/">http://www.cancer.gov/</a>	Yes.	No.	No.	No.	No.	
<b>Prostate Cancer Foundation</b> <a href="http://www.prostatecancerfoundation.org">http://www.prostatecancerfoundation.org</a>	Yes.	No.	Consideration of sexual function issues without reference to sexual practice or identity.	N/A	Yes, numerous links to websites and support groups	

## National gay men's health, AIDS/PLHIV (People Living with HIV) organisation websites

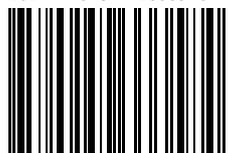
The following websites, which offer information and support to gay and other homosexually active men, and/or people with HIV, were also reviewed to determine whether they provided resources or information to men with prostate cancer.

- ACON (NSW GLBT Health Organisation)
- ACSA - AIDS Council of South Australia
- AIDS Action Council, ACT
- NAPWA - National Association of People Living with HIV/AIDS
- QAHC - Queensland Association of Healthy Communities
- Victorian AIDS Council/Gay Men's Health Centre
- WAAC - Western Australia AIDS Council



PROSTATE CANCER FOUNDATION OF AUSTRALIA  
LEVEL 3, 39-41 CHANDOS ST, ST LEONARDS NSW 2065  
[WWW.PCFA.ORG.AU](http://WWW.PCFA.ORG.AU)

ISBN 978-0-9923335-8-4



9 780992 333584 >