

Prostate Cancer and Gay and Bisexual Men: Social Science Research and Stakeholders

REPORT OF ONE-DAY WORKSHOP



Foreword

In spite of the vast amount of research into prostate cancer, there remains a significant gap in knowledge about the experiences and needs of Australian gay and bisexual men with prostate cancer and their partners. Prostate Cancer Foundation of Australia (PCFA) has previously commissioned research in this area and has also developed information for gay and bisexual men who have recently been diagnosed with the disease.

So, it is pleasing to see this preliminary work being built on by two much more extensive research studies: *Sexual wellbeing and quality of life after prostate cancer for gay and bisexual men and their partners*, funded by PCFA with financial support from the Movember Foundation; and *Mental health, resilience and sexual recovery among gay men with prostate cancer (the Moving On Project)*, funded by *beyondblue* also with financial support from the Movember Foundation. These studies will add considerably to our understanding of gay and bisexual men's prostate cancer experiences and needs and enable us to develop supportive care services to meet those needs.

This report covers a one-day workshop jointly convened by PCFA and the Australian Research Centre in Sex, Health and Society, which brought together social science researchers from these two studies and stakeholders to report on and discuss the excellent progress that has already been made.

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Chief Executive Officer, Prostate Cancer Foundation of Australia

Compiled by
Marie-Claire Cheron-Sauer and Gary Dowsett

Jointly convened by the Prostate Cancer Foundation of Australia
(Marie-Claire Cheron-Sauer, Director Support Programs)

and

The Australian Research Centre in Sex, Health and Society
(Professor Gary Dowsett, Deputy Director)

Held at the Australian Research Centre in Sex, Health and Society
La Trobe University, 215 Franklin St, Melbourne, VIC 3000
10:00am to 4:30pm, Friday 22 May 2015.

The Workshop

Research into the experiences and needs of gay/ bisexual (hereafter, GB) men diagnosed with prostate cancer (hereafter, PCa) and their partners/ carers is relatively undeveloped within Australia. Supportive care services to address their needs were also lacking until very recently. A number of social science researchers, over the last three to four years, with support from Prostate Cancer Foundation of Australia (PCFA) and *beyondblue*, and other key agencies have undertaken research into this area.

The workshop brought together the research teams from Australia's two main projects that have been exploring GB men and their partners' experiences of PCa, their collaborating partner organisations, and other key stakeholder and funders. Those projects are: 'Sexual Wellbeing and Quality of Life after Prostate Cancer for Gay and Bisexual Men and their Partners', led by Professor Jane Ussher with colleagues at University of Western Sydney and other institutions; and 'Moving On: Mental Health, Resilience and Sexual Recovery among Gay Men with Prostate Cancer', led by Professor Gary Dowsett with colleagues at the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University, Melbourne.

Workshop Aims

The aims of the workshop were to:

1. Provide a first opportunity to hear the outcomes of social science research currently being conducted with this population
2. Gain an understanding of achievements in the development of information and support for GB men dealing with PCa
3. Renew the collaboration between all stakeholders

4. Identify potential next steps in further research, research translation and training, and the development of culturally sensitive information and support for GB men dealing with PCa
5. Re-establish a small reference group of stakeholders, based on interest in continuing to inform research, information and support programs for GB men dealing with PCa.

Background

It is estimated that 17,250 cases of PCa will be diagnosed in Australia in 2015. It has also been estimated that between 3% and 5% of Australia men are gay (the number of bisexual men is unknown), suggesting that between 600 and 1,000 Australian gay men will be diagnosed with PCa this year. There is growing recognition that health promotion, health education and psycho-social interventions should address the concerns of GB men with PCa. However, there is a lack of empirical research to inform such services, and many GB men experience difficulty in expressing their concerns to health professionals, in particular their concerns about sexual wellbeing. Sexuality and intimacy are important aspects of an individual's quality of life, and there is a significant body of evidence to show that PCa can result in dramatic changes to sexual functioning, relationships, and sense of self, which can be among the most negative influences on the wellbeing of all men with PCa.

While the focus of previous research has been on heterosexual men, there is some evidence that GB men also experience significant changes to their sexual wellbeing after PCa, with reduction in sexual functioning, sexual satisfaction and quality of life reported to be greater for GB men than heterosexual men. However, these findings are based on small numbers of GB men, recruited

incidentally within larger heterosexual samples. This has led to GB men with PCa being described as an 'invisible diversity' or a 'hidden population', revealing a need for research on the impact of potentially important differences in sexuality, identity and intimate relationships on GB men's experience of PCa.

This may include: the importance of the prostate as a site of pleasure during anal sex; the significance of visible ejaculate for 'semen exchange' during sex; the need for a firmer erection for anal sex in comparison with vaginal sex; the consequences of anal discomfort and incontinence for receptive partners; complications arising from HIV status; the impact on the open nature of many GB

relationships; and the interaction of gay and masculine identity. However, these differences have been described as 'speculative', with 'future research needed to ascertain the impact of PCa on the lives of gay men', as this has implications for quality of life and psychological wellbeing. There is also a need for research to examine sexual wellbeing and identity changes in male partners of GB men with PCa, providing insight into their ability to cope and provide support.

The two research projects reported on here were funded in Australia in 2012-13 specifically to look at these questions for GB men.

Research Reports

Sexual Wellbeing and Quality of Life after Prostate Cancer for Gay and Bisexual Men and their Partners

Funded by PCFA New Concept Grant, 2013-2015.

Research Team: PI: Jane Ussher (UWS); CIs Janette Perz (UWS), Suzanne Chambers (Griffith, ANZUP), David Latini (Baylor College); AIs Ian Davies (Melbourne, ANZUP), Scott Williams (Melbourne, ANZUP), Ian Brotherton (ACON), Gary Dowsett (La Trobe). Research Officer - Duncan Rose.

AIMS: This exploratory study aimed to examine the psychological burden of changes to sexual wellbeing, quality of life (QoL), sexual identity and intimate relationships in GB men with PCa and their male partners, through a collaboration between leading University researchers and the Australian and New Zealand Urogenital and Prostate Cancer Trials Group (ANZUP).

DESIGN AND METHOD: This study involved two stages:

- 1 In-depth interviews with 46 GB men who have PCa, and interviews with seven partners, examining changes to sexual practices and identity, relational context and support, and interactions with health professionals, in the context of PCa, analysed through thematic analysis;
- 2 A series of reliable and well-validated standardized measures administered by survey to 124 GB men and 36 partners, in order to profile the sample, examine the relationship between QoL and sexual wellbeing, and

assess the suitability and acceptability of such measures for this population to be used in a larger international study. A comparison sample of 225 heterosexual men completed the standardised survey, with 44 men being interviewed.

Preliminary findings

Differences between gay/bisexual and heterosexual men

There were a number of differences between the relationship context of GB and heterosexual men: GB men were less likely to be in a long-term relationship of over 10 years (59% compared with 86%), were more likely to engage in casual sex (40% compared with 4%), and were more likely to have had two or more partners in the last six months (34% compared with 35).

Analysis of the standardised measures identified a number of statistically significant differences between GB men and heterosexual men. GB men reported lower psychological wellbeing, lower health related QoL, higher PCa-related distress, lower masculine self-esteem, and higher ejaculatory bother. However, GB men also reported higher sexual confidence, and higher sexual functioning before and after PCa.

GB men's subjective experience of changes to sexuality after PCa

GB men's subjective experience of PCa, elicited through in-depth interviews, has been organised under the theme of *sexual disqualification*. The physical changes resulting from PCa treatment – erectile dysfunction, loss of ejaculate, and reduction in penis size – were experienced as a 'defining moment' in many men's lives, leading to feelings

of feelings of loss, depression, life not worth living, failure, inferiority, and inadequacy. These changes also had an impact upon masculine and gay identity: threatening identity as a gay man, and impacting upon a sense of community/belonging. Finally, they had relational consequences, in terms of GB men's ability to attract a partner, maintain a relationship, perform sexually as expected, and look as expected.

Many men reported that they felt that they were aging before time, as they had an expectation of sex continuing in later life, something that PCa had curtailed. A number of men reported that PCa had cut short their exploration of gay sexuality/identity, as they had come out later in life.

In response to these changes, many GB men engaged in *sexual renegotiation*, involving new sexual practices, demonstrating sexual plasticity and flexibility. The response of partners to sexual changes was crucial, with partner acceptance or tolerance leading to continued sexual activity and relationships being stronger. Casual or long-term partners who were rejecting led to the man feeling rejected and isolated.

The majority of men reported that they sought information and support to deal with sexual changes after PCa. However, heteronormativity on the part of health professionals, and in some cases a refusal to discuss the impact of changes on gay sexuality, left many men feeling that their support needs were not being met. In cases where men received positive responses from health professionals, satisfaction with care and the ability to cope with sexual changes were higher.

Analysis of the results is continuing, and future directions identified include: the need to examine perspectives of clinicians, allied health workers and service providers; the need to develop and evaluate information and education for professional stakeholders; development and evaluation of information and support for GB men with PCa cancer and their partners; examination of broader LGBTI cancer experiences and perspectives.

Mental Health, Resilience and Sexual Recovery among Gay Men with Prostate Cancer (the Moving On Project)

Funded by beyondblue National Priority Driven Research Grant – Men's Stream, 2013-2015, supported by Movember

Research team: CIs Gary Dowsett (La Trobe), Duane Duncan (UNE), Garrett Prestage (UNSW and La Trobe). Research Officer - Daniel Du Plooy (La Trobe)

Depression is an issue for LGBTI people generally, with higher rates than the general population. Evidence is varied for sampling reasons and use of different measures. PCa diagnosis and treatment also lead to higher rates of depression and anxiety. There is evidence that the pre-existing experience of depression and anxiety are predictors of depression and anxiety after PCa diagnosis and treatment. We also know from heterosexual studies that female partners also have higher rates of depression and anxiety – but we do not know much about this in same-sex partnerships.

There are three areas where the quality of life of gay men experiencing PCa is affected: (1) sexuality and identity; (2) self-perception after PCa and broader relationships and community; and (3) the experience of PCa from diagnosis to an ongoing state of 'living-with' PCa.

1. Among those gay men who had experienced clinically diagnosed depression before PCa, the experience of PCa was secondary to the depression. Older men appeared to accept the negative sexual consequences of PCa as an aspect of aging, whereas younger men described fighting to return to 'normal'. The literature on men's experiences of the consequences of PCa understands sexual difficulties as a loss of, or damage to, a patient's masculinity. Instead, among the gay men interviewed for this project, the challenges posed by changes in sexual function extended

beyond a narrow notion of masculinity focused on penetrative (implicitly heterosexual) sex, to a threat to their identities as gay men. For these men, a gay identity was hard won, and insofar as it was conceived of in terms of one's sexual practice or orientation, men also described the social dimensions of that identity. According to these men, PCa poses an existential threat to the coherence of the self, striking not only their sexual function, but their relationship to partners, gay community, and the symbolic resources shaping gay men's identities more generally.

2. For gay men, a sense of self is provided by an alignment between sexual function, a functioning body that has never or infrequently faltered, the wider social and gay community and its support structures, and a legacy of political and cultural ideas about the coherency of a gay self. The challenge PCa poses to this sense of self is pronounced, particularly among younger men and those whose identity, sexual practice and sense of self was closely connected to a gay community network. Gay community and its social fields were described as unsupportive and discriminatory by some men experiencing sexual difficulties following PCa; others reported gay community as fostering resilient responses to PCa, including the support provided by structures of close gay friends and sexual partners. The dominant framing of PCa as an disease that affects individual, mostly heterosexual men, not only excludes consideration of gay men's experiences, but also excludes wider understanding of the ways in which the social relations and material conditions of daily life shape illness. These findings suggest that research and support mechanisms that seek to include gay men will be inadequate to the task if they fail to reflect on the ways in which these men's experiences of PCa are shaped by the largely marginal social worlds of gay community settings.
3. The issues in PCa about being gay start at the moment of diagnosis, both in assumptions about men's sexuality and then about

heterosexuality if a gay man has not 'come out'. We observed not just systematic heterosexism, but also, active work by gay men to manage the doctor/patient relationship, omitting information so as to save someone else discomfort or embarrassment.

In summary:

- The experience of gay men diagnosed with, and treated for, PCa is different from that of heterosexual men, who dominate in the literature.
- The mental health consequences of PCa for gay men are best understood in relation to the threat the illness poses to gay men's sense of identity, and relationship to other gay men and a gay community network.
- Systemic discrimination in the health system, supported by wider processes of social marginalisation, stigma and discrimination, further undermine the hard-won identities of gay men with PCa.
- Gay men experience forms of exclusion from the moment of diagnosis through successive practices of treatment, care and management, and also describe the isolation created by a gap in recognition of their illness by gay community support and health organisations.
- Gay men are compelled to conceal or manage information about their sexualities in clinical health settings in ways that perpetuate a discursive silence regarding their experience. This discursive silence is further sustained in gay community health settings where PCa does not feature as an important health issue in the way HIV/AIDS and sexual health does. These issues contribute to the sense of a loss of self that participants in this project identified.
- This discursive silence also seems to contribute to a problem in recruiting gay men, and especially gay male partners of gay men, for research on these issues. This potentially inhibits the research still needing to be done on the impact on PCa in gay men.

Summary

Summary of the Prostate Cancer Foundation of Australia's Achievements in the Development of Information and Support for Gay and Bisexual men with Prostate Cancer

Overview of the Prostate Cancer Foundation of Australia (PCFA)

PCFA is a broad based community organisation and the peak body for PCa in Australia. Its mission is to reduce the impact of PCa on Australian men, their partners and families and the wider community, recognising the diversity of the community. It does this in three ways:

1. Funding world leading research aimed at preventing and minimising the impact of PCa
2. Raising awareness of PCa through major awareness campaigns and engagement with community and governments
3. Providing information and support through the development of evidence based resources for men and women, a PCa specialist nursing program and support groups across Australia

PCFA is currently in a new phase of strategic development and has set itself a number of new priorities for the next three to five years, which build on the achievements of the previous strategic plan. These include:

1. Broadening our engagement with the community through the provision of information and support to diverse groups within the community.

2. Ensuring timely access to evidence based and culturally sensitive information about PCa to men and women across Australia
3. Continuing to build our brand and visibility in the community
4. Strengthening our advocacy initiatives
5. Broadening our outreach and support activities to provide meaningful and accessible information and support to men and women across Australia, including the provision of online information and support
6. Diversifying our research program to include a three way focus on basic science, clinical research and survivorship research.

The PCFA Gay/Bi Men's Initiative

As part of its strategy to broaden engagement and provide information and support to diverse communities affected by PCa, PCFA undertook significant work from 2012 to develop evidence based resources and support groups for GB men affected by PCa. This work was initiated by the immediate past PCFA National Chairman, David Sandoe OAM, who, through discussions with colleagues in the USA, became aware of a significant gap in our knowledge base about the information and support needs of GB men dealing with PCa and in the availability of evidence based and culturally sensitive information for them.

Research was commissioned at that stage for two specific pieces of work, which were conducted by ARCSHS, and included:

1. An audit of existing resources and websites providing information to GB men with PCa
2. An examination of the PCa health information and promotion needs of Australian GB men

The findings from these two studies were published in 2013, in a PCFA monograph, entitled: *Prostate Cancer Information Needs of Australian Gay and Bisexual Men*. The monograph is available from PCFA.

The findings of these two studies pointed to a dearth of information and support specifically addressing the needs of GB men dealing with PCa and led to the formation of the PCFA Gay/Bi-sexual Initiative, which included a range of stakeholders and which focused on the development of specific resources and the development of specific support groups for GB men with PCa.

The evidence-based GB men's specific resource was launched in August 2014 in Sydney. It consists of four booklets, each focusing on the following four areas: Diagnosis, Treatment, Side Effects and Maintaining Wellbeing. Copies of the pack are available from the PCFA in hard copy format or as a USB. It is also available from the PCFA website.

Support groups for GB men have been established in Sydney, Melbourne, Brisbane, Adelaide, Perth and Darwin. The establishment of these groups was supported by the work of Greg Millan, Men's Health consultant, throughout 2012 and 2013, who worked with PCFA national and state-based teams to hold a series of community information events for GB men to raise awareness of PCa and engage with the local community to establish these groups, which are peer facilitated, with some support from PCFA staff.

In 2014, a similar process was undertaken to establish support groups in regional areas. Unfortunately, groups were not established following the information events. This highlighted the challenges facing GB men of being open about their sexuality in smaller regional communities. The information sessions were not well attended, group leaders could not be identified and there was little

uptake on the concept of a PCa support group specifically for GB men in these communities.

Other approaches for providing accessible and meaningful support for GB men are being progressed, with a telephone support group currently in development and the development of online forums for information and support.

PCFA is currently partnering with the Sydney-based GB group 'Shine-a-Light' to deliver a series of PCa awareness sessions to GB men in NSW throughout 2015. This pilot program has been made possible by a community grant from the Aurora Foundation and it is anticipated that it will be replicated across the country.

Since 2011, PCFA has had a presence at the Sydney-based Fair Day, a community event attended by over 80,000 people as part of the Sydney Gay and Lesbian Mardi Gras in February each year. Since 2012, we have partnered with the Sydney Shine-a-Light Group for this event and in 2015, we partnered also with Cancer Council NSW, following the development of a Memorandum of Understanding between PCFA and Cancer Council NSW. The success of this partnership in 2015 has led to the development of plans for a bigger presence in 2016 at Fair Day and the Mardi Gras, with a greater focus on raising awareness of PCa to the LGBT community

For the first time in 2015, PCFA also had a presence at Fair Day in Perth, Western Australia. Though a smaller event, with approximately 15,000 people in attendance, this was a great opportunity to showcase PCFA's work in this area and to collaborate with the LGBTI community in Western Australia. We anticipate that in future, PCFA will have a presence at other significant community events for the LGBTI community in all major metropolitan and regional cities.

Workshop Participants

Attendees	Organisation	Contact Details
Marie-Claire Cheron-Sauer	Prostate Cancer Foundation of Australia (PCFA)	mccheronsauer@optusnet.com.au
Veronica Collins	Andrology Australia	veronica.collins@monash.edu
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Apologies

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Greg Millan	Men's Health Services	greg@menshealthservices.com.au

Gay and Bisexual Men's and Related Initiatives Currently Carried Out by Participating Organisations

Beyondblue

- Funding the *Moving On* project (the project noted above based at ARCSHS) and continuing with knowledge translation
- How we integrate this knowledge into what we do as an advocacy, health promotion and funding organisation

Cancer Council NSW

- State based organization starting to work together with shared publications
- Looking at support needs of GB men since 2006, had peer support program offering 1:1 peer support, grant funding to promote programs to include stories of our volunteers, moved into LGBTI space and develop an advisory committee with yearly deliverables – ACON inclusive training participation with staff, LGBTI landing page that promotes the supportive care programs offered, discussion paper on LGBTI, webinar to address the Gay and Lesbian voice in the community, moving into the anal cancer space, partners in NHMRC research programs

Cancer Connect at Cancer Council Victoria

Cancer connect is a free and confidential one to one telephone peer support program that links people affected by cancer to a trained volunteer who has been through a similar experience. Volunteers offer emotional and practical support and provide understanding at a time when it is most needed. Cancer Connect provides the opportunity to be matched with a volunteer as similar as possible in age, cancer experience, treatment choices and other important factors such as sexuality or fertility.

The support is available for:

- People recently diagnosed with cancer
- People who have completed treatment
- Family and friends of people with a cancer diagnosis
- People carrying a gene that increases their risk of developing cancer

Talking to a volunteer can help reduce feelings of isolation and anxiety and improve relationships with health professionals.

Cancer Council Victoria is interested in further expanding Cancer Connect for the gay and bisexual communities.

ACON

- Advocate for sexuality to be included in data collection and research
- Research program within policy department, specific research ethics community to assist engagement with participation and translation of research
- Support individuals and link into suitable care, not sure how to record data into the future
- HIV data collection
- Connect in with support groups and delivery of guest speakers
- Aging program and Mature Aged Gay Men (MAGM)

VAC/GMHC

- Positively Living with HIV Program
- PCa has not been a focus in the past

Movember

- Provide funding for GAP initiative for global collaborative research initiatives
- Lead TrueNorth which is a care model built up across the globe to address unmet needs of men with PCa (e.g. sexual health, ED, decision support)
- Model is aligned with carers/partners, access to information to allow informed decision making, piloting integrated health care program (Peter MacCallum Cancer Centre, Continence Foundation)

- Learning from crossover of programs, particular younger men
- Utilizing resources from PCFA, program to include lifestyle factors

Andrology Australia

- Veronica Collins, scientific writer/reviewer of resources; CEO Carol Holden; six other staff
- Funded through Australian Government Department of Health (since 2000)
- Mission: 'Andrology Australia will undertake those measures that will enhance men's health and well-being by addressing disorders of the male reproductive system and associated conditions through programs of *community* and *professional education* and support of research'.
- Focus on male reproductive health, specifically prostate disease including cancer, erectile dysfunction/sexual dysfunction, testicular cancer, male infertility and androgen use and misuse
- Delivery through website (www.andrologyaustralia.org), online education, and downloadable and print resources
- Limited resources on PCa: refer to other organizations for specialist knowledge and resources
- Interested in collaborating with other organisations in the area of GB men's health
- Where we could be more involved is in the area of GP, nurse/allied health professional education, e.g. 'Engaging Men' clinical resource for GPs
- Also interested in being part of any coordinated awareness campaigns across organisations.

Gay and Lesbian Health Victoria

- Funded 10 years ago in response to reports
- Research programs; private lives LGBTI health area, specific questions on PCa for the first time to be included in the Private Lives 2, safe schools collision to become GLBTI inclusive schools coverage in Victoria
- Rainbow Network- related to GLBTI in schools, 4,500 people undertook training last year, Aged Care, diversity through AFL campaign
- Online resources
- Research into practice and practice into research
- Community partner in the Moving On project

Further Information

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