

**Body Image and Self Esteem Following a Prostate Cancer Diagnosis:  
Perspectives According to Sexual Orientation**

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## **Abstract**

Gay men diagnosed with prostate cancer are not a readily identifiable group. This thesis is designed to explore the proposition that gay and straight men might experience the psychosocial aspects of prostate cancer differently. Positioned in a theoretical framework of health-related stigma, it was designed to investigate the ways in which the burden of diagnosis and treatment of prostate cancer are experienced by gay men.

To explore this, three studies of different methodology were used: a systematic review to find published literature concerning the quality of life of gay men diagnosed with prostate cancer, an online focus group for gay men to determine the needs and challenges of gay men diagnosed with prostate cancer, and an online survey to compare body image, self-esteem, urinary function and sexual function in gay and straight populations with and without a diagnosis of prostate cancer.

Four papers fulfilled the criteria for inclusion in the systematic review, which showed that sexual orientation impacts the quality of life of gay men in a unique way.

Focus group results identified several factors (such as the emotional response to a prostate cancer diagnosis, access to help and support, and the impact of sexual changes on identity) which, because of resulting stigma, affect the ability to improve quality of care.

Counter-intuitively, the internet survey findings showed no significant differences between gay and straight men with prostate cancer in measures of body image, self-esteem, sexual function or urinary function, but did show differences in men with a diagnosis of prostate cancer compared to those without, regardless of sexual orientation.

Prostate cancer appears to affect the quality of life of gay men in unique ways, affecting their ability to maximise quality of care because of associated stigma.

## **Statement of Authorship**

Except where reference is made in the text of the thesis (noting in particular Chapter 6 which has been published in a peer-reviewed journal) this thesis contains no material published elsewhere or extracted in whole or in part from a thesis submitted for the award of any other degree or diploma. No other person's work has been used without due acknowledgment in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

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## **Dedication**

This entire thesis is dedicated to my three sisters, Bronwyn, Catherine and Elizabeth who have helped and encouraged me along the PhD journey. Without their amazing efforts this thesis could not have been completed.

## Definition of key terms

*Appearance evaluation* relates to the feeling of physical attractiveness or satisfaction with one's looks (21).

*Body Image* is a person's mental opinion or description of his or her own physical appearance. It also involves the reactions of others toward that person's physical body based on what is perceived by that person (22). 'Body image is a multidimensional construct that encompasses self-perceptions and attitudes (i.e. thoughts, feelings and behaviours) vis-à-vis (with regard to) one's own body, especially but not limited to one's physical appearance' (page 279)(23). Body image is defined as a patients' subjective perceptions of their physical appearance (24).

*Decisional regret* the fear of making a decision-in regard to prostate cancer treatment- that will later be regretted. In a study concerning treatment for localised prostate cancer by Steginga 18% of men feared making a decision that would later be regretted (25).

*Gay* = Homosexual. A person with a sexual desire or behaviour directed toward a person or persons of the same sex.

*Health evaluation* is concerned with the feeling of physical health and freedom from physical illness (21).

*Health orientation* relates to the extent of investment in a physically healthy lifestyle (21).

*Health related quality of life*

*Hegemonic masculinity* refers to the dominant masculine style which is dependent on cultural setting and historical period (26). Hegemonic masculinity subordinates women's activities and other alternative forms of masculinity (e.g. effeminate masculinity) (26). The concept of hegemonic masculinity might be correlated with macho masculinity as demonstrated in the film characters Rambo, Rocky and The Terminator (26) That is, rather than being the lived reality, hegemonic masculinity is an aspirational goal (26).

*Localised prostate cancer* is that condition where the cancer is confined within the prostate gland and has not yet spread to involve other body areas.

*MSM* Men who have sex with men

*Metastatic prostate cancer* is an advanced form of the cancer which has spread beyond the prostate gland to the lymph nodes, soft tissue, or to the bones. The bone, lung and liver are the most frequent sites of distant prostate cancer metastases (27).

### *Quality of Life*

*Self-esteem*, an ability to reflect one's own emotional evaluation or worth, is both an attitude and a judgement with positive or negative evaluation towards the self (28).

*Sexual function* Normal sexual function in males involves several discrete components: libido, initiating and maintaining erection, orgasm, ejaculation and the refractory period (29). While sexual function is unaltered by a diagnosis of prostate cancer per se, various d treatments can impact on normal sexual functioning (30, 31).

*Straight* is equivalent to *Heterosexual*. A person with a sexual desire or behaviour directed toward a person or persons of the opposite sex.

*Urinary function* Normal urinary function may be altered following prostate cancer treatments (32). The urinary system regulates fluid volume, blood pressure, metabolic wastes and drug excretion. The normal daily urine output is 1,500ml.

*Wellbeing* "A state of well-being (mental health) in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community"(33).



## **Chapter 1: Rationale for the research**

In this chapter an introduction to the study is provided, and the rationale, aims and objectives of the thesis are presented.

More than 1.1 million cases of prostate cancer were recorded worldwide in 2012, accounting for around 8 percent of all new cancer cases and 15 percent of new cancer cases in men (1).

The 2012 Australian estimates show prostate cancer to be the most common type of cancer (excluding basal and squamous cell cancers) diagnosed in the Australian population, accounting for 15 per cent of the total burden of cancer in Australian men, second only to lung cancer (2, 3). The incidence of prostate cancer, the number of new cases diagnosed in a particular year, was 21,808 cases in 2009 (4). Between 1982 and 2009, there was an overall 144% increase in the incidence of prostate cancer in Australian men (5).

For the period 2006-2010, the Australian five year survival rate following a diagnosis of prostate cancer was 92% (6). For Australian men, prostate cancer was the underlying cause of 4.4% of all male deaths registered in 2011. Male deaths from this underlying cause have increased gradually from 2,852 in 2002 to 3,294 in 2011. The median age at death for prostate cancer has steadily increased from 79.4 years in 2002 to 81.8 years in 2011, and the current median age at death for prostate cancer is close to the median age for all deaths related to any cause (81.5 years) (7). This is probably because prostate cancer is typically slow-growing and many men who have received a diagnosis of prostate cancer will live for many years with the consequences of its progression or the results of treatment interventions (8).

### *Risk factors for prostate cancer*

To date, apart from the obvious characteristic of male sex, there are only three risk factors for prostate cancer which have been firmly established; these non-modifiable risks include age, race and a family history of prostate cancer (9).

### *Health disparities for prostate cancer*

The broad list of determinants of health include: education, income, health insurance, geographic location, access to care, gender, age, ethnicity, communication skills (language), health literacy, particular disease state (e.g. Asthma, HIV/AIDS, prostate cancer, lung cancer), relationship status, co-morbidities, legal issues, stigma and social attitudes particularly in relation to minority groups.<sup>1</sup> This wide-ranging catalogue of factors which impinge on an individual's overall health outcome are known as the determinants of health.

Courtenay suggests factors such as economic status, ethnicity, educational level sexual orientation and social context influence the kind of masculinity that men construct (10). A wide range of health disparities have been reported among adults identifying as straight (heterosexual), gay (homosexual) or lesbian, or bisexual (11). However the cancer literature has, until recently, overlooked this important variable and as long as cancer incidence is not recorded by sexual orientation, the question of cancer disparities remains undiscussed (12). In the context of the current study, the side effects of prostate cancer treatments together with their associated stigma contribute to a variation in perceived masculinities (10).

### **Aims of the research**

The current work aims to investigate the ways in which the psychosocial burden of the diagnosis and treatment of prostate cancer are experienced by gay men and to assess whether this experience is similar to that of straight (heterosexual) men. While there is no evidence to suggest prostate cancer is linked to sexual orientation, few published papers have examined the way in which the experience of prostate cancer might be influenced by sexual orientation (13-18).

The thesis has been designed to provide an original contribution to knowledge by investigating issues of unease and concern for gay men diagnosed with prostate cancer. It is anticipated that investigation with regard to self-identified sexual orientation may provide opportunity for improvement in overall management of all men diagnosed with prostate cancer regardless of sexual orientation. Recognition of

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<sup>1</sup> Supervisors note: we know that the intention was to reference this point, probably with the World Health Organization website 'The determinants of health', available at <http://www.who.int/hia/evidence/doh/en/>.

the diversity of the cancer experience may lead to the optimization of cancer treatment with corresponding appropriate outcomes.

An “invisible diversity” is how the author Thomas Blank referred to gay men who have been diagnosed with prostate cancer, as little is known of the way in which this group experiences prostate cancer (19). While some aspects of the impact of prostate cancer are likely to be sexual-orientation neutral, the degree of difference or similarity of the straight and gay populations in dealing with outcomes remains unknown (20).

Consistent with the aim described above, the question to be addressed in this thesis is: How does a gay sexual orientation influence body image and self-esteem following a prostate cancer diagnosis?

### **Objectives**

Three studies using different methods were undertaken as a multi-faceted approach to this investigation.

The specific objectives of the current research were to:

- 1) Conduct a systematic review to identify all published literature concerning the quality of life of gay men diagnosed with prostate cancer.
- 2) To conduct a qualitative study using an online focus group method to determine the needs and challenges of gay men diagnosed with prostate cancer.
- 3) To conduct a quantitative study using a cross sectional online survey methodology to compare body image, self-esteem, urinary function and sexual function in gay and straight populations with and without a diagnosis of prostate cancer.

### **Organisation of the thesis**

In this opening chapter the research question to be answered by the thesis has been presented as: How does a gay sexual orientation influence body image and self esteem following a prostate cancer diagnosis?

Chapter 2 gives an introduction to the clinical aspects of prostate cancer and then expands to the areas of diagnosis, staging systems, treatment and treatment side effects. In Chapter 3 the psychosocial impact of prostate cancer is considered with regard to anxiety, depression, and distress, fear of prostate cancer return, PSA anxiety, regret, cultural setting, sexual orientation and masculinity. Chapter 4 positions prostate cancer within a framework of stigma theory. Chapter 5 gives an outline of the research methodology used for the three studies, with chapters 6, 7 and 8 presenting details of a Systematic Review, an on-line Focus Group study, and an Internet-based cross sectional study respectively. Chapter 9 presents a Discussion and brief Conclusions concerning the findings from all three studies.

## **Summary and Conclusions**

The rationale for the thesis has been presented in this introductory chapter. An overview of the available literature suggests that little work has been undertaken in the area of prostate cancer and sexual orientation. The main aim of the current research is to investigate how a gay sexual orientation impacts on body image and self esteem following a diagnosis of prostate cancer. In the following chapter an introduction to the clinical aspects of prostate cancer are presented with an explanation of staging systems, treatments and side effects.

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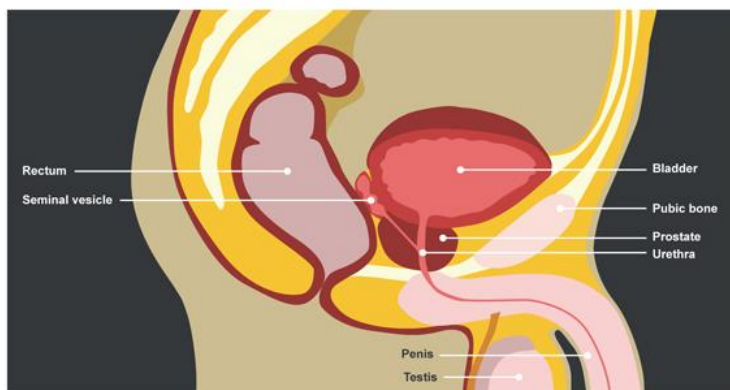
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## Chapter 2: Prostate Cancer, an introduction and treatment options

Chapter 1 presented an outline of rationale, aims and objectives of the thesis.

In this chapter an outline of the clinical aspects is given together with an explanation of staging systems, treatments and possible corresponding side effects in relation to prostate cancer.

Figure 1 Male pelvic anatomy



Reproduced with permission from Australian Prostate Cancer Research, 2013

The prostate gland is part of the male reproductive system, the main function of which is to secrete the slightly alkaline fluid that forms part of the seminal fluid that carries sperm. Prostate cancer, a potentially life-threatening disorder, is a male specific disease which affects the prostate gland. As shown in Figure 1, the prostate sits deep within the male pelvis beneath the bladder. The urethra, which drains urine from the bladder, passes through the prostate and the anatomical positioning of the prostate makes treatment interventions difficult to perform and often associated with side effects. A tumour results when cells of the prostate reproduce at an abnormally high rate. Localised prostate cancer is considered to be that condition where the tumour cells are confined within the prostate gland and have not yet spread to involve other body areas (p. 72) (2). Although prostate cancer is typically slow growing, once the cancer cells have escaped from the prostate and have invaded other distant parts of the body, particularly the bones and lymph nodes, secondary tumours are produced (3). This process is known as metastasis.



### *Prostate cancer Diagnosis and Staging System*

Prostate cancer generally affects the older male, particularly those over the age of 50 years and remains an ever present and increasing possibility as men age (4). The early stages of prostate cancer are often asymptomatic, and diagnosis relies on a number of indicators. Digital rectal examination (DRE) to determine the texture of the surface of the prostate gland (which can be altered in the presence of prostate cancer) plus a blood test to ascertain the level of Prostate Specific Antigen (PSA) is the most effective way to detect prostate cancer early (p. 148) (1). PSA is a glycoprotein produced within the prostate and is quantifiable by a blood test (p. 144) (1). An abnormal DRE and/or PSA result indicates the need for a prostate biopsy. Newer tests which aim to provide additional information in the staging process have recently become available. These include a blood test to aid in clinical decision-making called the Prostate Health Index (phi) which is now available. The phi which considers three different forms of PSA (total PSA, free PSA and a precursor of PSA known as p2PSA), is able to identify appropriate biopsy candidates (5). It is the expectation that the phi test will decrease the number of prostate biopsies. The phi test has particular value in predicting the likelihood of prostate cancer progression during active surveillance (5).

When a biopsy is required, a number of core samples are taken from the prostate to determine the presence of cancerous cells. Cells are then classified according to the Gleason scoring system. This system relies on the “appearance” of the cells of the prostate biopsy sample (p. 56) (2). The Gleason score is obtained by summing two numbers. The first number is the most predominant pattern of prostate cancer and the second number is the second most predominant pattern. Each grade is out of 5 and therefore the total Gleason score can be in the range 2 to 10, being the sum of the two grades (p. 56-57) (2). Less aggressive disease is indicated by lower scores of 2 to 4. Scores of 5 to 7 indicate intermediate disease while aggressive disease is indicated by scores between 8 and 10 (p. 56-57) (2).

Prostate cancer severity is usually classified according to the Tumour-Node-Metastasis (TNM) staging system (2, 6), see box 1. This is achieved using the combined information obtained from the results of the DRE, radiology tests, Gleason score, and PSA values. This classification identifies the aggressiveness of the prostate cancer and as such will be suggestive of appropriate treatment. However, difficulty arises in that there is not simply one appropriate treatment for each of the prostate cancer stages.

## Prostate cancer treatment

Although there are a number of treatment choices available for localised prostate cancer, those currently undertaken in Australia include active surveillance, prostatectomy, brachytherapy (radioactive seeds), and external beam radiation therapy (EBRT) plus or minus androgen deprivation therapy (ADT) (7). While there are other forms of treatment available apart from those listed, these are not widely used in Australia to date.

### **Box 1. The Tumour-Node-Metastasis (TNM) classification system**

**T1** (sub-groups T1a, T1b, T1c) Tumour is small. It cannot be felt by the doctor and may have been detected on needle biopsy, initiated after a raised PSA test. Usually there are no symptoms.

**T2** (sub-groups T2a, T2b, T2c) Tumour is large enough for a doctor to feel, but is thought to be confined to the prostate gland.

**T3** (sub-groups T3a, T3b) Tumour extends beyond the prostate and may have invaded the seminal vesicles.

**T4** (sub-groups T4a, T4b) Tumour invades other tissues beyond the prostate in the pelvic region.

**N0** No spread to regional lymph nodes

**N1 to 3** Tumour is present in the lymph nodes (glands) in the pelvis.

**M0** No distant metastasis

**M1** (sub-groups M1a, M1b, M1c) Tumour cells present in bone or other distant organs of the body' (1).

### *Active surveillance*

Following a prostate cancer diagnosis, proven by biopsy, some men can be appropriately managed with an active surveillance protocol that may avoid or delay treatment (p. 240) (1). Continued monitoring by regular PSA, DRE and usually repeat biopsy, in a planned timeframe helps assess any change in the characteristics of the cancer during the active

surveillance period (p. 74) (2). If the prostate cancer becomes a higher risk it is then treated. Active surveillance is an important management strategy for men diagnosed with low-risk prostate cancer (9). Declining to undertake surgical or radiotherapy interventions is a choice made in the context of the extent and aggressiveness of the cancer, age at diagnosis, current age and associated co-morbidities. Risk stratification, using clinical characteristics, and PSA kinetics, must be strictly monitored to ensure timely recognition of potentially aggressive disease (10). Active surveillance allows a biopsy confirmed prostate cancer to remain in situ until changes in PSA and cancer grade are detected. However whilst worry and fear may potentially give rise to psychological problems, Burnet and van den Bergh found that active surveillance was not associated with greater psychological distress than more immediate treatment for prostate cancer (11, 12). For low-risk prostate cancer, Ritch et al showed that for a group of men between 66 and 69 years with no co-morbidities, between 2004 and 2009 there was a slight increase in the use of active surveillance (13). Evans et al have shown that in Victoria, Australia, between 2008 and 2011, for a group of men up to 12 months post diagnosis, 40.6% who had been diagnosed as having low risk of progression had received no active treatment (8). Whether the 'no active treatment' constituted 'active surveillance' remains unclear and is a particular limitation of Evan's study (8). 'The need for active surveillance is increasing due to the awareness that many prostate cancers are identified that show low growth potential and therefore are likely to remain clinically asymptomatic during the lifetime of an individual' (page 296) (9).

### *Prostatectomy*

Prostatectomy is the surgical excision of the complete prostate gland. It is usually performed using one of three techniques (open, laparoscopic or robotic assisted laparoscopic). The term 'radical' prostatectomy is employed in relation to this procedure to signify that the entire prostate, together with the adjacent seminal vesicles, have been removed (14).

### *Brachytherapy*

Brachytherapy is described as 'a radiotherapeutic strategy in which radioisotopes are inserted directly into a cancer-bearing organ so that high doses of radiation are delivered to the malignancy with relative sparing of the surrounding normal tissue (15). In the realm of prostate cancer, brachytherapy is a treatment form where radioisotope seeds or implants are

inserted into the prostate to deliver localised radiotherapy (2). Brachytherapy is a suitable treatment option when the risk of localised prostate cancer recurrence is considered to be low or intermediate (16).

#### *External Beam Radiation Therapy (EBRT).*

External Beam Radiation Therapy (EBRT) involves the use of radiation treatment delivered from an external source. Such a delivery system which minimises injury to organs surrounding the prostate uses high-energy radiation from an energy source outside the body to kill cancer cells (1). The ability to completely destroy the cancer is a limiting factor for radiation use. Results are dependent on the size of the cancer or the number of cancer cells present (1). Radiation damage accumulates over time resulting in a worsening of side effects (1). Since therapy involves weekday treatments over many weeks, the logistics of attendance for treatment may be problematic for some men.

#### *Androgen Deprivation Therapy (ADT)*

ADT suppresses the production of the male hormone testosterone. It is sometimes used in combination with EBRT. ADT may be employed in the treatment of locally advanced and metastatic prostate cancer (17).

### **Treatment side effects**

The common post treatment side effects are those associated with sexual function, urinary function and hormone related issues.

#### *Sexual side effects*

Impotence (erectile dysfunction (ED) can result following a number of different prostate cancer treatments (18). Although impotence may improve over a number of years following surgical treatment, return to base-line potency is not seen in the majority of cases (19). Potency recovery is dependent on patient age, pre-operative potency status and extent of neurovascular bundle preservation but independent of pathological stage of the prostate cancer (20). Erectile dysfunction can often worsen over time for men who have received radiotherapy (21). Research has shown that erectile dysfunction in men with prostate cancer can have long lasting psychological effects (22). Such dysfunction has a substantial impact on quality of life of these men (23). All men experience the loss of ejaculate post prostatectomy

as the prostate and seminal vesicles which are responsible for the production of fluid which forms part of the semen are removed during a prostatectomy. While orgasm remains possible even though ejaculatory capacity is at zero, the absence of ejaculate can compromise a sense of male identity and evoke distress (24). Wittmann et al describe erectile dysfunction as the failure to achieve and maintain a penile erection sufficient to attain satisfactory sexual relations and sexual dysfunction as a loss of pleasure and diminution in sexual ability and activity and loss of pleasure (25). Consequently, men undergoing treatment for prostate cancer often develop sexual dysfunction as a response to erectile dysfunction. This altered sexual ability can evoke embarrassment, fear, diminished confidence, a deep sense of loss, awkwardness and a feeling of vulnerability (26).

#### *Urinary incontinence*

Following surgery, the rate of urinary incontinence is variable, having been reported at 5-35% in one study and between 25 to 75% in a further study(2) (27).

Research concerning urinary incontinence after radical retropubic prostatectomy (RRP) by Sacco et al used three definitions for the actual rate of continence (28). These definitions were: (A) no or occasional pad use (B) 0 or 1 pad used daily, but for occasional dribbling only (C) more than 2 pads used per day. The findings of this study showed a progressive improvement in continence until two years from RRP but some patients can become incontinent later (28). In this study at 24 months follow-up 83%, 92.3% and 93.4% of men achieved continence according to the definitions (A)-(C) as above.

Urinary incontinence during sexual stimulation and release of urine during sexual climax (climacturia) have all been reported as common side effects of prostatectomy (29-31). Following a radical prostatectomy, a fifth of the prostate cancer survivors had orgasm-associated urinary incontinence (32). Living with such long-term residual symptoms of prostate cancer treatment suggests that survivors face significant quality of life issues (33).

#### *Androgen deprivation treatment (ADT) side effects*

ADT which is sometimes used as a combined treatment with External Beam Radiation Therapy (EBRT) to treat localized prostate cancer, is associated with adverse effects which include increased fracture risk, hot flushes, gynecomastia, serum lipid changes and memory loss (34). Erectile dysfunction and loss of libido are also side effects associated with the use of ADT (35). While changes in body composition, obesity, insulin resistance and

hypertension have emerged as complications of ADT, the position of cardiotoxicity as a significant side effect of ADT remains unclear (36).

### *Treatment decision making*

Clinical information (PSA, DRE, biopsy, Gleason score) enables a prostate cancer risk assessment to be made. Although a degree of risk (very low, low, medium/moderate, high) can be assigned to a particular prostate cancer case, this is not definitive and can alter with time (p207) (1). When diagnosed with localized prostate cancer a man may be asked to make a decision between the treatment options themselves. The need to make such a choice is unusual in cancer care as set protocols are normally followed for each particular cancer type. The need to choose a particular treatment type can result in significant anxiety or treatment decision regret, for many men and their families.

### *Treatment choice via a decision aid*

At the time of diagnosis of localized prostate cancer when there is more than one medically reasonable treatment option, a decision aid can prepare men to have an informed discussion with their doctor concerning treatment options (37). Treatment decision is strongly influenced by physician recommendation, advice from family and friends, information obtained from books, journals and the internet (38). Pros and cons of all prostate cancer treatment options should be presented by the treating physician to decrease the risk of subsequent treatment regret (39). Robles et al found that patients' treatment choices are influenced by patient beliefs, and the beliefs of others regarding the disease, the effectiveness of treatment and the severity of possible side effects (40). Zeliadt et al concluded that variations in treatment decisions may be more indicative of the differences in the information patients receive rather than truly reflective of underlying patient preferences (41). The study by Sidana et al of a younger cohort of men (<50 years) found that their doctor's recommendation and the internet were the most frequent sources of information which guided the decision regarding treatment choice (42). While these studies identified information as being a priority in decision making, sexual orientation was not listed as a factor in treatment choice. Resource availability influences information quality which in turn will be driven by socio-economic factors (43). It might be expected that those of higher income and higher education level would access information regarding prostate cancer treatments and side effects more readily than those from a lower socio-economic background. Hu et al found that treatment regret was associated

with a fear of cancer recurrence, less spirituality and longer interval since treatment and non-white race (44).

Kane et al suggest that doctor information concerning treatments might be more readily sought, understood and acted upon by those of a higher education level (45). Other factors including age, prostate cancer aggressiveness, co-morbidities and personal relationships would be expected to have a bearing on treatment decision making.

### *Summary*

This chapter has offered an overview of prostate cancer. The range of diagnoses, staging system, treatment options and possible treatment side effects has been discussed. Decision making concerning treatment choices has been considered.

Prostate cancer treatments which may result in numerous psychosocial and relationship side effects are explored in greater detail in the following chapter, Chapter 3.

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### **Chapter 3: Psychosocial impact of prostate cancer**

Clinical and treatment aspects of prostate cancer were introduced in Chapter 2. Chapter 3 provides a description of an array of psychosocial issues which may be experienced post prostate cancer diagnosis. This range may include psychological concerns, outcome regret, the impact of sexual orientation, and/or issues concerning masculinity, body image, self-esteem and relationships.

#### **Anxiety, depression, distress and suicide**

Psychological aspects of survivorship have been documented in relation to a number of cancer site specific issues (1-4). Where the site and treatment outcomes are likely to impact on a man's sexual function as is the case in prostate cancer, psychological concerns are particularly relevant (5-7).

The prevalence of patient depression and anxiety across the entire prostate cancer treatment spectrum (pre-treatment, on-treatment and post-treatment) is relatively high (8). Studies have also shown that partners of patients with prostate cancer are affected by psychological distress (9) (10). A range of peer-reviewed literature reported various rates of anxiety and depression in the prostate cancer population. This discrepancy of rates appears to be related to the actual time to assessment following diagnosis and the complexities of different constructs ostensibly assessed by the different assessment tools employed in each of the different studies (11-13). Jayadevappa et al reported that 8.5% of men newly diagnosed with prostate cancer also had a diagnosis of depression (11). The work by Punnen found levels of mild depression or anxiety which ranged from 3-16% over time while baseline levels of elevated distress ranged from 8-20% (12). The study by Carlson found more elevated levels with approximately 30% of men with prostate cancer experiencing clinically relevant general distress (13). A review study by Bloch et al<sup>2</sup> was unable to draw conclusions about the psychological adjustment to prostate cancer yet other studies have found high levels of psychological distress (1, 14, 15). Research by Latini et al found that prostate cancer related anxiety has strongly reduced time to undertake treatment (16). Anxiety has also been

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<sup>2</sup> Reference not included by candidate however discussed with supervisors: Bloch S, Love A, Macvean M, Duchesne G, Couper J, Kissane D: Psychological adjustment of men with prostate cancer: a review of the literature. *Biopsychosoc Med* 2007, 1:2.

implicated in men managed in the 'active surveillance' category, with some active surveillance candidates opting earlier for radical treatment (16). Work by Bill-Axelssonork indicates that distress was common in both post prostatectomy and active surveillance cohorts (17).

Prostate cancer is a significant risk factor for late life suicide (18). Research by Misono et al showed that a diagnosis of prostate cancer may increase the immediate risks of suicide and cardiovascular death (19).

In the research by Mehnert, 16% of patients reported increased levels of psychological distress (3). Fear of prostate cancer recurrence, which is one of the major psychosocial concerns of prostate cancer survivors, may impose a burden on men before and after treatment (20-22). A number of factors including the way in which post-treatment symptoms impinge on quality of life, having concerns about the presence of cancer itself, and fears regarding the possibility of a recurrence of cancer, can all contribute to psychosocial distress. (23).

The study by Roth concluded that for men diagnosed with prostate cancer psychological distress is influenced by sexual dysfunction, urinary incontinence, bowel changes, fatigue, pain, hot flashes, body image changes and forced lifestyle changes (p 565) (24). Smith et al have shown that men diagnosed with prostate cancer have high unmet psychological needs as well as high unmet sexuality needs (25). This study mirrored an earlier work by Steginga et al who found that following a prostate cancer diagnosis and subsequent treatment, 33% of the members from prostate cancer self-help groups in Queensland, Australia had a high need for help in multiple domains including sexuality, psychology and health system and information areas (26). Despite these findings men with prostate cancer tend to avoid the services of mental health agencies (27).

PSA anxiety is common among prostate cancer survivors and the risk of depressive symptoms or general distress might be increased by the persistence of PSA anxiety (28). The high degree of anxiety evoked by PSA testing might have its onset weeks before the required PSA test (29).

The fear of cancer recurrence can impose a significant burden upon patients before and after treatment (p. 1931) (20). Enhanced provision of care for men with prostate cancer may be

attained by an understanding of men's fears about cancer recurrence and how these fears translate to physical and mental health (21).

### **Body image**

Profound physical and functional changes can accompany some types of prostate cancer treatments (30). These changes can be particularly evident with androgen deprivation therapy (ADT). Such deleterious side effects occur because of the reduction of testosterone to castrate levels. Typical ADT induced physical side effects include loss of muscle mass, weight gain, increase in adiposity, breast tenderness and enlargement, loss of penile length or volume and loss of testicular mass. Alterations to function include hot flashes, decreased cognitive function, fatigue and depression (30, 31).

Hopwood et al propose that an important endpoint in quality of life evaluation is that of *body image* as cancer treatment may result in major changes to patients' appearance from disfiguring surgery, late effects of radiotherapy or adverse effects of systemic treatment (p. 189) (32). Taylor-Ford et al conclude that body image is an important component of the prostate cancer experience and that there is a suggestion that body image has a meaningful association with quality of life among prostate cancer survivors (33). Research has also shown that the degree of body image dissatisfaction in relation to prostate cancer can be influenced by the type of treatment received (34). Harrington reported that men who received androgen deprivation therapy (ADT) to treat prostate cancer had a greater degree of body image dissatisfaction than those who were ADT naïve (34). While limited data are available concerning body image and prostate cancer, there is a gap in the research knowledge when sexual orientation is considered concurrently (33, 34). An additional research omission has been identified by Lee in relation to post-prostate cancer-treatment quality of life (QoL) for men-who-have sex-with-men (MSM). Lee suggests that assessment of QoL in MSM may not be accurately reflected by assessment tools designed for the heterosexual population (35).

Kousari-Rad and McLaren suggest that the high level of body image dissatisfaction among gay men, in the general community, is due to the emphasis on physical attractiveness in the gay community (36). Their conclusions were based on a large Australian sample of men from the general community ranging in age from 18-63 years (mean 31 years).

Given that there have not been any appropriately validated quality of life instruments for use with gay men this thesis has been designed to examine body image and self-esteem.

Beren et al reported that gay men have more body dissatisfaction and more distress in many psychosocial areas related to body dissatisfaction compared with straight men (37). Consistent with previous studies, findings by Peplau et al support the hypothesis that gay men are at greater risk than straight men of experiencing body image dissatisfaction (38). The earlier work by Levesque and Vichesky likewise suggested that gay men are at particular risk for body image dissatisfaction (39). Although the research by Hausmann et al showed no difference between gay and straight men on measures of body image, it is highly likely that any dissatisfaction experienced would be exacerbated by prostate cancer (40). Such a heightened sense of body image dissatisfaction may increase an individual's notion of stigma resulting in a decreased quality of life (QoL). The Multi-center AIDS Cohort Study in Chicago completed towards the end of the HIV crisis in 1997, found that while between-group differences exist, the gay cohort of the study was neither particularly low in global self-esteem nor high in psychological distress (41). The applicability of these findings to the current day is extremely tenuous as community attitudes and laws have altered in the 21 years since the study was conducted (for example same sex marriage, initially granted in the Netherlands in 2001 and in various USA states, beginning with Massachusetts, since 2004).

### **Self esteem**

Self-esteem is generally considered to be a personality trait that reflects a person's overall sense of value and self-worth. Cuncic describes self-esteem as that which involves how you generally feel about yourself, your abilities, appearance, emotions, attributes and behaviours (42). Similarly Carlock describes self-esteem as the way you feel about yourself and that most people have a global feeling about themselves which runs along a continuum from high to low, good to bad (43).

### **Social and relationship issues**

Research is limited regarding ways men best adjust to a diagnosis of prostate cancer (44). The experience of partnered or married straight men will differ from that of single straight men and the majority of gay men who do not live with long-term partners (45). For a minority group such as gay men, information regarding such adjustment is sparse (44). For heterosexual men it is likely that the main role of social support will be taken up by the man's wife or partner. Importantly, survivors of localised prostate cancer who have initially experienced higher levels of social support were predicted to have better emotional well-



being later in the cancer journey (46). The social support for gay men is more likely to be connected within a network of friendships and the broader gay, lesbian, bisexual and transgender (GLBT) community (45). There are apparently no data available regarding the proportion of either gay or straight men with prostate cancer that are in a long-term relationship.

Relationships can be impacted by prostate cancer (47, 48). A literature review by Couper et al suggests that female partners of men diagnosed with prostate cancer report more distress than the men themselves, yet these women believe that their male partners are more distressed (49). Chambers et al reported that correlates of distress after a prostate cancer diagnosis differ between patients and female partners. For men, masculine self esteem may be most crucial for men, whereas for women, her partner's level of distress may matter most (50).

A review by Galbraith et al found that couples who are survivors of prostate cancer are faced with interruptions in their intimate relationships, communication, and overall quality of life (p. 300) (51). Beck reported that the physical side effects and associated stressors following diagnosis and treatment for prostate cancer can interfere with the sexual intimacy of couples (52). A small exploratory study by Hartman found that following prostatectomy the three gay couples of the study acknowledged a change in sexual experience, expressed strategies to accommodate such change and were able to comment on the degree of acceptance of change in sexual experience (53).

### **Treatment regret and needs post prostate cancer diagnosis**

A study by Davison and another study by Hu indicated that some men felt a sense of regret about the course of action –treatment- which had been undertaken following the prostate cancer diagnosis (54, 55). In the study by Davison et al, patients had received surgical treatment while the treatment modalities for those in the study by Hu et al included radical prostatectomy, brachytherapy, external beam radiation, and watchful waiting (54, 55). Men expressing regret had a poorer health related quality of life than those not expressing such an attitude (55). Erectile dysfunction and urinary incontinence, the major and immediate side effects of surgical intervention to treat prostate cancer, are common post prostatectomy (56). This result can evoke a sense of profound loss accompanied by grief and mourning (57). The study by Diefenbach showed that while the initial levels of decisional regret were low they increased significantly between 6 and 12 months after diagnosis and men who had a prostatectomy showed a substantial increase in regret compared with those who had been

treated via external beam radiation or brachytherapy (58). This outcome suggests that treatment-related regret is associated with perceptions of patient sexual and urinary dysfunction and activity limitation rather than measures of objective functioning (58).

The study by Steginga et al showed that the closer a man was to the time of prostate cancer diagnosis the greater need for help in the physical and daily living domain (26). This study concluded that having prostate cancer that is not in remission, having received radiotherapy, and having lower levels of education were predictive of greater need for help in patient care and support (26). The research by Boberg et al found that care delivery, support needs and information needs were all areas of varying concern to men with prostate cancer (59). Ream et al reported that the areas of greatest need are related to psychological distress, sexuality-related issues and management of enduring lower urinary tract symptoms (60). Similarly Smith et al concluded that attention should be given to sexual and psychological needs in the early months after diagnosis or treatment of prostate cancer, particularly in younger men, those with less education, and those having surgery (25).

A number of studies were designed to investigate the needs of men in relation to prostate cancer diagnosis and treatment, without regard to sexual orientation, found that generally the domains of sexuality, psychology, health systems and information were the areas of prostate cancer acknowledged as requiring particular help (25, 26, 59, 60).

### **The impact of sexual orientation**

Currently, few studies have examined the experience of gay men coping with prostate cancer (61-68). The American Cancer Society Prostate Cancer Survivorship Care guidelines suggest that more research is required to understand the unique needs and concerns of same sex couples in relation to prostate cancer (28).

The study by Rosenberger et al showed that gay men have a diverse sexual repertoire with sexual behaviours not limited to acts of penile insertion (69). While some authors suggest that erectile dysfunction is particularly problematic for gay men as the penis may not be firm enough to penetrate the anal sphincter, this is not the complete picture. While not all gay men engage in penetrative sex, the repertoire of other activities of this group ensures that erectile dysfunction, and hence sexual dysfunction, remain problematic for gay men (69).

Research by Wassersug et al found that for men who have sex with men, concerns regarding side effects of prostate cancer treatment were similar to that of straight men yet there was more significant bother by the loss of ejaculation and therefore greater risk of depression or anxiety in the former group (66).

A number of gay men diagnosed with prostate cancer feel that they are damaged goods and no longer desirable for sexual encounters (64). Such perception may be compounded by lack of emotional support at this vulnerable time. The Rosenberger study reported that 54% of the gay men and 56% of the bisexual men in a large cohort were single, suggesting that a large number of these non-heterosexual men do not have available support at the time of prostate cancer diagnosis (69). The research by O'Shaughnessy et al suggested that in relation to prostate cancer recurrence, men without partners are more likely to be distressed than their partnered contemporaries (70).

### **The impact on masculinity**

There are many forms of masculinity, 'some hegemonic, some marginalized, some stigmatised and some consumption-led, rather than a single masculinity' (71). Research by Sand et al found that men's perceptions of masculinity differed substantially from stereotypes in the literature. Men reported that being seen as honorable, self-reliant, and respected by friends were important determinants of self-perceived masculinity (72).

Men are strongly impacted by the dramatic change in sexual capacity following prostate cancer treatment and are forced to reconfigure their masculinity (73-75). Thompson suggests that there are different kinds of masculinities evident in society, and we ought not to speak of masculinity as a singular term (76). Although sexual performance and masculine identities are interwoven, the hegemonic version of masculinity, with its hetero-normative approach can be problematic when considered in relation to gay men diagnosed with prostate cancer (76). As suggested in Chapter One, hegemonic masculinity is an aspirational goal rather than a lived reality.

Commentary by Broom suggests that experiences of masculinity are affected to varying degrees by prostate cancer and its treatment processes (77). While masculine identity is undermined by loss of sexual intimacy, the perception and redefinition of masculinity is further eroded by an inability to project self-confidence following a loss of sexual capability (78). The perception of one's own masculinity is therefore no longer clear, resulting in the

need for an identity reassessment. The lack of research concerning prostate cancer when experienced by gay men suggests that Moynihan is accurate in her assessment of the way that such investigation has almost exclusively employed a hegemonic approach to this important issue of men's health. However, gay men may not adhere to that which is commonly perceived to be stereotypically masculine.

Moynihan suggests that the stereotypes of masculinity inform research design, data collection, analysis, conclusions and men's own responses-(p1072) (79).

Broom supports this concept by suggesting that the idealised version of masculinity is linked to the dominance of heterosexuality (77). For prostate cancer survivors, diminished masculinity is a prominent yet understudied concern (6). Galdas suggests that a more inclusive framework of masculinity should be adopted by moving beyond the hegemonic analytical lens which is consistently western and white-centric (80). There is a need 'to gain greater understanding of the barriers and triggers associated with the decision making process of help seeking behaviour in men who experience illness' (80). Wall and Kristjanson have proposed that the current form of hegemonic masculinity, which they believe to be limited and lacking in clarity, be re-framed into a picture of masculinity as a dynamic and contextual construct (81).

Research by Roesch supports the hypothesis -that individuals who confront their illness in a direct way, either emotionally or instrumentally, reap both psychological and physical benefits, whereas those who do not are apt to experience increasing psychological and physical pain- (82). While the ability to cope in the light of a prostate cancer diagnosis is most important, the resulting quality of life will be determined by inter-related variables including individual personality, cultural associations, masculinity, body image and sexual behavior. Halkitis et al demonstrated that for a cohort of HIV positive gay men the concept of masculinity is closely linked to physical appearance (body image) and sexual adventurousness (83). It is likely that such close associations would follow in terms of prostate cancer.

Such association between body image and masculinity and the requirement to reframe masculinity as outlined above would suggest that in the genre of prostate cancer and sexual orientation, body image is an outcome variable requiring further investigation.

Importantly, the psychological well-being of gay men may differ in ways that are not tapped by existing measures or paradigms reflecting the salience of developing a stigmatised

identity, the different configurations of emotional and sexual intimacy characterizing gay men's interpersonal worlds, or the psychological impact of the HIV epidemic (76). This would suggest that a construct of prostate cancer defined in terms of a heterosexually focused masculinity is inappropriate across a minority sexual orientation group such as gay men. A more suitable construct to evoke a deeper understanding of the outcomes of prostate cancer would consider body image and self-esteem in light of sexual orientation. Such an investigation is the focus of the study described in Chapter 8.

### **Summary and conclusions**

In this chapter, prostate cancer has been examined through the lens of the psychosocial impact on a range of issues including anxiety, depression, distress, fear, regret and sexual orientation in relation to impact on health outcome. Sexual orientation has been identified as a particular area in the realm of prostate cancer where little research has been undertaken. It has been suggested that the current restrictive concept of hegemonic masculinity which excludes minority groups such as gay men is inappropriate. It is anticipated that a more accurate appraisal of prostate cancer outcomes will emerge by consideration of body image and self-esteem with regard to sexual orientation.

The following chapter, which positions prostate cancer and sexual orientation within the theoretical paradigm of health-related stigma, provides a framework on which the thesis research will be constructed.

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## **Chapter 4: Prostate cancer, a theoretical position.**

As discussed in Chapter 3 defining prostate cancer in terms of heterosexually focused masculinity is inappropriate for gay men and that body image and self-esteem outcomes are more appropriately considered in the light of sexual orientation. In this chapter the theoretical position of prostate cancer, with respect to these, is presented with prostate cancer initially positioned within the theoretical domain of stigma with respect to: (i) health, (ii) cancer in general, and (iii) sexual orientation. In the final section of this chapter, prostate cancer is considered within the domain of masculinity theory.

### *Stigma theory*

Stigma, which is a constantly changing multidisciplinary social process, has been applied to an array of circumstances resulting in a variety of definitions (1-3). Ascribing one theoretical position to encompass the many facets of health-related stigma, in the current context, would not permit full coverage of this important issue. Therefore, the works of a number of theorists have been used to examine aspects of stigma within the context of prostate cancer.

Goffman describes three different types of stigma; firstly, stigma associated with physical deformities, secondly, stigma associated with blemishes of character such as rigid beliefs and dishonesty and thirdly, stigma connected with tribe such as race or religion (4) . Those individuals in society who do not depart from particular expectations are called “normals”.

Goffman’s theory of stigma would suggest that gay men diagnosed with prostate cancer are susceptible to stigma on two levels. Firstly, there is the stigma associated with having a diagnosis of prostate cancer and secondly the stigma associated with belonging to the gay sexual minority. Attributes associated with gay men diagnosed with prostate cancer may cause such a person to be deemed as undesirable or stigmatised by others who consider themselves as ‘normals’.

As the five year survival rate following a diagnosis of prostate cancer is high at 92%, the individual diagnosed with prostate cancer will remain forever as the one who has been diagnosed with cancer; the one who is forever different (5). Such a tainted perception may

give rise to stigma from the self (internalise stigma/internalised homophobia) and/or from an external source (external stigma) (6).

Stigma theory has undergone important shifts in definition and characterisation from that presented by Goffman in the 1960s (4, 6, 7). Link and Phelan have proposed a more updated version describing stigma in terms of a convergence of five interrelated components which are: (i) labelling (as people identify and label human differences), (ii) stereotyping, (iii) separation via the mentality of “them” and “us” (allowing the formation of groups), (iv) loss of status, and (v) an exercise of power (8). Fife et al describe stigma as subjectively experienced in multiple ways that are partially dependent upon the nature of the stigmatizing condition and the social circumstances of the individual (6). Scambler describes stigma as typically a experienced or anticipated social process, with characteristic exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group (3). Associated psychological costs as described by Else-Quest are particularly important as - the experience of self-blame can be experienced as internalized stigma (9).

The stress of stigma, self-blame and perceived blame from others” can all be experienced by cancer patients (10). A cancer diagnosis and the perceptions of others, that is, the possible external stigmatization, is ‘likely to become an important part of an individual’s identity’(p. 65) (10). Phelan et al found that for colorectal cancer, stigma and self-blame are problems for a significant minority of men (10). Similarly, it might reasonably be expected that stigma and self-blame would be issues of concern for men diagnosed with prostate cancer.

#### *(i) Stigma and Health*

Marlow defines health-related stigma as stigmatisation of an illness, as occurred with AIDS/HIV. which can be applied to an individual or a group of people with the illness, as well as to the illness more generally, (11-13)- (p285)(14). Illness can incur stigma as it represents potential for physical limitations, as per AIDS/HIV, to be associated with particular negative images (6). Weiss describes such health-related stigma as ‘typically characterized by social disqualification of individuals and populations who are identified with particular health problems’ (p277)(15). Weiss further suggests that such stigma contributes to a hidden burden of illness (15).

#### *(ii) Stigma and cancer*

The stigma associated with cancer, while less overt than for some conditions such as HIV/AIDS, may be present to a varying extent in the lives of diagnosed individuals (6). Schroyen et al suggest that patients with cancer face pathology-related stigmas due to the negative representations of cancer (especially some types of cancer such as lung cancer) (16). Chapple et al reported that patients with lung cancer have felt stigmatized whether they were smokers or not, because lung cancer is strongly associated with smoking (17).-Those who had never smoked or had stopped smoking years ago felt unjustly blamed for their illness-(p1470)(17). Research by Gray concerning a cohort of men with prostate cancer who had been treated with prostatectomy, reported that there is a stigma associated with a diagnosis of prostate cancer (p273) (18). As with lung cancer where there is an association with smoking, prostate cancer is associated with sexual dysfunction thereby making negative judgments more likely (18).

Demographic features of a person's identity such as ethnicity or socio-economic status can add to the health-related stigmatisation previously encountered by a diagnosis of cancer (15, 16, 19).

### *(iii) Stigma and sexual orientation*

The role of sexual orientation which, in the arena of prostate cancer has been overlooked until recently, should be viewed as a variable interwoven with many others rather than being considered as a simple statistical characteristic (20-22).

An insight into the psychosocial impact of prostate cancer on gay men may be gained by considering the effect of the assault of stigma in the response to the diagnosis of cancer in general, the diagnosis of prostate cancer, and the disclosure of gay orientation. As prostate cancer is usually diagnosed in those men aged over 50, the disclosure of such a diagnosis will have its own age related stigma from within the gay community where youth, attractiveness and sexual prowess are of paramount importance (23, 24). The aesthetically-orientated nature of gay culture as described by Drummond suggests that sexual impotence and urinary incontinence which may result from prostate cancer treatment are also unacceptable in the gay world (23). In an attempt to shed the coatings of stigma associated with prostate cancer, openly gay men, who have previously undergone an initial "coming out" process where sexual orientation was disclosed, are faced with a second "coming out" in revealing a prostate cancer diagnosis.



Scambler suggests that enduring features of identity (e.g. race, ethnicity, sexual preferences) have their own accompanying stigma apart from an actual health-related condition (3).

#### *(iv) Stigma and prostate cancer*

Gannon describes hegemonic masculinity as that which ‘refers to the dominant understanding of what it is to be a man at a given place and time and represents the model of masculinity that a particular society considers as “true” maleness’ (25). In Western societies these traits of maleness include a ‘suppression of needs, refusal to acknowledge pain, denial of weakness or vulnerability, emotional and physical control, the appearance of being strong and robust, reluctance to seek help, interest in and focus on penetrative sex and the display of aggressive behaviour linked to physical dominance’ (25). Applying the framework of health-related stigma to the loss of masculinity in the aftermath of prostate cancer treatment permits a convenient, yet biased, interpretation of outcomes (9, 18, 26-29). As outlined by Wall, this current restrictive concept of hegemonic masculinity, which excludes minority groups such as gay men, is inappropriate for the positioning of a theoretical construct (30). Therefore, a quantitative assessment of masculinity will not be undertaken, but rather the impact of prostate cancer on the psychological wellbeing of men so diagnosed will be investigated by an evaluation of self-esteem and body image.

#### *Stigma management*

The theorists Goffman and Newton both divide stigma into that which is discrediting and that which is discreditable (4, 33).

A *discrediting* stigma is one which is initially evident such as an obvious physical disability.

A *discreditable* stigma is one which is not immediately evident such as incontinence and erectile dysfunction.

Fergus has shown that for some men, the invisibility of sexual dysfunction (a discreditable stigma), experienced by some men following prostate cancer treatment, might actually be seen as a benefit or an advantage in that such invisibility may enable improved coping with altered self-esteem and confidence (29).

Goffman similarly described the two techniques of “passing” and “covering”, which a person may employ to hide a potentially stigmatising condition (4).

“*Passing*” occurs when the stigmatised condition can be concealed from others (e.g. sexual dysfunction). Many men adopt “passing” to avoid disclosure of their prostate cancer due to fear of stigmatisation (34).

“*Covering*” occurs when only certain aspects of the condition are revealed. Covering prevents the stigma from being the central focus of life (33).

Chenard describes the three stigma management strategies adopted from the work by Goffman as: selective disclosure, pre-emptive or open disclosure, and reactive disclosure (4, 35). Selective disclosure refers to an incremental disclosure to a select group over time. Pre-emptive or open disclosure refers to a proactive disclosure of prostate cancer status. Reactive disclosure entails the concealment of a prostate cancer diagnosis to protect against stigma (36). While these strategies have been proposed in relation to challenges associated with belonging to a gay sexual minority, they are also applicable in dealing with a diagnosis of prostate cancer.

Some men may limit disclosure of prostate cancer due to a ‘low perceived need for support, fear of stigmatisation, the need to minimize the threat of illness to aid coping, practical necessities in the workplace, and the desire to avoid burdening others’(18). Such fear of a disease-associated stigma adds to the burden of stress which already exists following a diagnosis of prostate cancer. This increased stress might worsen outcomes such as an ability to work or lead a normal social life (8).

### *Masculinity theory*

The study by Sand et al has shown that the stereotypical perception of masculinity (erectile function, penile length, ejaculation and continence) was not matched by a large international cohort of men (n=27, 839) who considered honour, self-reliance and respect by friends to be essential determinants of self-perceived masculinity (37). While describing the boundaries of hegemonic masculinity as narrow and limiting, the findings of this study add to the criticism of the theoretical concept of hegemonic masculinity (culturally dominant within the field of masculinity) as outlined by Connell and Messerschmidt (38). Coles suggests that few men actually meet the hegemonic ideal (39). However, as will be indicated later in the thesis, hegemonic masculinity is more an aspirational goal rather than an achievable reality. McVittie and Willock write that the notion of hegemonic masculinity prevails in discussions of (good) health (40). Yet, when ill health is discussed, men transition between hegemonic

and subordinate identities and the delay in seeking help is related to this transition (40). Zaidler et al found that ‘one-third of men had lost a dimension of their masculinity following treatment’ and for those ‘whose spouses perceived low marital affection’, diminished masculinity and sexual bother was strongest (26).

Appleton et al write that while hegemonic masculinity shapes men’s health behaviour, ‘individuals adopt other forms of masculinity and negotiate deviations from social norms to fit the situation’ (41).

### *Summary and conclusion*

As men’s sexuality and masculinity are highly interwoven, a loss of sexual capacity associated with prostate cancer treatment results in a need to re-construct a disrupted masculinity (26, 29). As gay and straight sexualities are different, these re-structured masculinities must be different. This masculinity difference would imply that the stigma experienced throughout the trajectory of prostate cancer is therefore different. The implication being that the experience of gay and straight men diagnosed with prostate cancer differs and accordingly suggests that the wellbeing of these two groups of men would be divergent. In this thesis differences in wellbeing are examined in terms of body image and self-esteem.

Positioning prostate cancer within the theoretical framework of health-related stigma has given rise to the study question “How does a gay sexual orientation influence body image and self-esteem following a prostate cancer diagnosis?”

Details of the research method employed to investigate the study question are outlined in the following chapter (Chapter 5).

A detailed explanation of each of the three research methods is presented in Chapter 6 (Systematic review), Chapter 7 (Qualitative study) and Chapter 8 (Quantitative study).

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## **Chapter 5: Research Methodology**

There is little evidence regarding the experience of prostate cancer when considered in terms of sexual orientation (1-5). To explore this area a mixed method study has been employed in the thesis research. This method involved the collection, analysis and integration (or combination) of both quantitative and qualitative data to address the “Rationale for the research” and research objectives as presented in Chapter 1 (6). Data triangulation, the use of different methods and data sources, permits multiple perceptions to clarify meaning. In this thesis, triangulation has been used by identifying different ways to investigate how sexual orientation might influence body image and self-esteem following a prostate cancer diagnosis (7). The review, synthesis and interpretation of a particular question from different perspectives is possible using data triangulation is a valuable approach when traditional research –for example, a randomized control trial- is not possible or appropriate as in the current enquiry . In this chapter, an outline is given of the three investigative methods used to address the research question “How does a gay sexual orientation influence body image and self esteem following a prostate cancer diagnosis?”

### **Research design**

The triangulated study components were:

- i) A systematic review was conducted and designed to determine the issues of concern for gay men diagnosed with prostate cancer (presented in Chapter 6).
- ii) A focus group study of gay men previously diagnosed with prostate cancer (presented in Chapter 7).
- iii) An internet based cross sectional questionnaire study to investigate self-esteem, body image, sexual and urinary functions of men classified by sexual orientation and prostate cancer status (presented in Chapter 8).

The rationale for these three study components are described in detail below with precise methods presented in each relevant chapter.



## **The Systematic Review**

Systematic reviews appear at the top of a hierarchy of evidence and permit the validity of findings of different research methods to be ranked and provide the best possible estimate of any true effect (8). In ways which limit bias, scientific strategies are applied to all relevant studies that address the specific clinical question of the systematic review through the assembly, critically appraisal, and synthesis of all relevant studies that address a specific clinical question (9). As such, the three dimensions of evidence evaluation; effectiveness, appropriateness and feasibility, are accounted for at the highest level (10). Systematic reviews enable large amounts of information to be synthesised into more manageable portions and are often less costly and quicker to undertake than commencing a new study, thereby allowing faster implementation of effective diagnostic or treatment strategies (11).

As the systematic review is a powerful research tool in its ability to; establish the generalisability of scientific findings, permit the assessment of the consistency of relationships, reduce random and systematic errors of bias and enable replication of results, it was employed as one of the components of the triangulation research method to identify peer-reviewed published research on the concerns of gay men diagnosed with prostate cancer (11).

The absence of appropriate studies was an early stage difficulty. A number of studies have dealt with issues relating to a diagnosis of prostate cancer, yet few have stratified according to self-identified sexual orientation (12-16). Such an initial finding suggested an assumed hetero-normative approach exists in the area of prostate cancer research.

## **The Focus Group Study**

The unique online aspect of the study was chosen as gay and bisexual men with a diagnosis of prostate cancer are difficult to locate and engage within the general community. Conducting the focus group study by this method enabled men geographically scattered throughout Australia to take part in this study. The online asynchronous nature of the study encouraged men to post comments, thoughts and ideas onto the group notice board at times convenient to themselves. Such a method of posting responses permitted greater flexibility regarding time commitment. This focus group was one where time was not of the essence, unlike the time constraints that might be necessary and expected during an in-depth interview or a face to face focus group. The nature of the focus group allowed individual respondents

time to compose answers and comments regarding the questions of the facilitator or the postings of the other members of the focus group. The focus group was well received with all participants posting discussion points concerning the experience of prostate cancer. This study, permitted issues of concern to be voiced by a minority (gay) group, gave direction to the type of enquiry to be employed in the first phase of this research.

### **Internet based cross sectional questionnaire Study**

*This study was given the initial working title of “The Australian Men’s Body Image, Self-Esteem and Prostate Cancer Study”*

An online survey using an on-line survey facility (“Survey Monkey”) was employed as the most effective and practical way of sourcing information concerning health issues of a large group of Australian men for this study. This method was low cost compared with more traditional hard copy (postal and data entry) methods. The online approach allowed participants to enter their own data thus reducing the possibility of data entry error. Collection of data online, as recommended by Kleinmann, enabled participants to complete the survey in private at a convenient time with a rapid return rate possible (18). The eligibility criteria were not onerous and were stated as: Men living in Australia, equal to or greater than 30 yrs of age, with or without prostate cancer diagnosis, with or without treatment.

As previous prostate cancer research has not always considered co-morbidity effects and overall health status, the current survey included questions used in a previous study (16) to address these issues.

Those who had previously been diagnosed with prostate cancer were asked to complete a further section of the survey concerning issues which had been encountered following such a diagnosis.

As an extensive search failed to locate a body image scale applicable to all men regardless of prostate cancer status, sections of Cash’s “Multidimensional Body-Self Relations Questionnaire” (MBSRQ), a well-validated self-report inventory for the assessment of body image, was employed in the current study (21-23). While no evidence of validation of the MBSRQ within a prostate cancer cohort could be found, this questionnaire was thought to be the most suitable of those currently available. Importantly, this decision was made as the MBSRQ did not give one numerical answer for body image but rather resulted in values for

subscales within the construct thereby increasing the likelihood of detection of differences between the four groups of men. The three subscales of the MBSRQ which were chosen as being the most relevant were: Appearance evaluation, Health evaluation and Health orientation.

The domains adopted for the study investigation were: Sexual function, Urinary function, Self esteem and Body image.

#### *Sexual function and Urinary function*

The Australian study by Holden et al indicated a prevalence of significant lower urinary tract symptoms (age standardised at 16%), erectile dysfunction (21%) and prostate disease (14%) (p218) (24). While men living with prostate cancer frequently report poor sexual and urinary functioning it must be assumed that this sub-group is not wholly responsible for the figures concerning urinary tract symptoms and erectile dysfunction as outlined by Holden study (16, 25, 26). It was therefore reasoned that a number of men from the “no diagnosis of prostate cancer” group must be contributing to the statistics regarding erectile dysfunction and/or urinary dysfunction. An appropriate scale to determine sexual and urinary function, applicable to all men regardless of prostate cancer diagnosis, was then sought.

The Expanded Prostate Cancer Index Composite (EPIC) of 50 questions, developed by Wei et al to measure the health related quality of life among men with prostate cancer, was considered to be the most suitable scale (20). This scale has been validated in men with localised prostate cancer who had undergone surgery, external beam radiation or brachytherapy with or without the use of androgen deprivation therapy (ADT, hormonal therapy). Although the complete EPIC instrument broadly measured urinary, bowel, sexual and hormonal symptoms, this current research investigated solely urinary and sexual functions given that such functions were possibly relevant to all men regardless of prostate cancer status. The measure of bowel and hormonal symptoms measured by EPIC were more appropriate only to a select group of men post prostate cancer treatment and were therefore omitted from the current investigation.

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## **Chapter 6: Systematic Review**

This chapter presents the first aspect of the research, a systematic review to explore the question, “How does the diagnosis of prostate cancer impact the quality of life of gay men?” The findings of the review were written and published in a peer-reviewed paper titled “A systematic review of the quality of life of gay men diagnosed with prostate cancer”(1). This paper is presented below.

### **Introduction**

Prostate cancer is the most common cancer diagnosis in Australia (excluding non-melanocytic skin cancer) (2). It has major morbidities associated with treatment including failed cancer control, incontinence of bladder and bowel, sexual dysfunction, and psychological trauma (3). These morbidities are extant in all of the different prostate cancer treatment modalities. The experience of prostate cancer in the context of sexual orientation remains an area of concern, as investigation in this regard has been overlooked until recently (4-6). The absence of routine collection of sexual orientation data in large-scale cancer registries makes this area of research problematic (7).

Altered psychological function for those diagnosed with prostate cancer, may be attributable to a number of predisposing factors including age at diagnosis, fear of cancer recurrence, type of treatment selected, and existing social supports (8-10). Arguably, sexual orientation should be included as studies have shown that in the general population, gay men have a greater likelihood of depression than do straight men (11). These findings would suggest that when the burden of a prostate cancer diagnosis is added to this mix, an outcome disparity would be expected. At the time of writing, there are no published data indicating that gay and straight men are diagnosed with prostate cancer at a different rate: yet gay men remain a subpopulation under-represented in prostate cancer research (4, 12).

It is important to address this limited attention; a gay couple has a 28% chance of one member being diagnosed with prostate cancer in their lifetime, and a 3% chance of both members being diagnosed (13).

While previous research suggests that the type of primary prostate cancer treatment experienced will be indicative of quality of life (QoL) outcomes, this systematic review was designed to investigate the influence of sexual orientation on QoL (3, 4, 14-20). Publications concerning quality of life which highlighted the differences in experiences and needs of gay men compared with those of straight men in relation to prostate cancer formed an important part of the review.

## **Aim**

To systematically examine literature that has explored the impact of a prostate cancer diagnosis on the quality of life of gay men.

## *Systematic review question*

The systematic review question was, 'How does the diagnosis of prostate cancer impact the quality of life of gay men?'

## **Methods**

### **Eligibility criteria**

Inclusion criteria for this review included English language qualitative and quantitative publications of papers, conference reports, theses, dissertations and grey literature concerning self-identified gay men diagnosed with prostate cancer.

The search time-frame was 1 December 1992 to 1 December 2012.

### **Search strategy**

In order to minimise the risk of bias, this systematic review included published and grey literature and studies using both quantitative or qualitative research methods.

### Databases

PubMed, PsycInfo, Medline, and CINAHL databases were searched in all fields using the search terms 'prostat\*', 'gay', 'homosex\*' and 'quality of life'.

### **Grey literature**



OpenGrey, OpenDOAR, Science.gov, Scirus and MedNar databases were used to search for grey literature using the search terms 'prostate cancer', 'sexual orientation', 'gay', 'homosexual', 'cancer', 'wellness', 'quality of life' and 'sexuality'.

University repositories were searched as outlined in Appendix 6.1

In addition to the database searches above, searches were conducted to access electronic and print formats not controlled by commercial publishers. These included theses and dissertations, conference proceedings, newsletters, reports, government documents and repository content (including universities) (Appendix 6.1). Research repository websites, which included conferences symposia and theses collections, were searched using the terms 'prostate cancer', 'sexual orientation', 'gay', 'homosexual', 'cancer', 'wellness', 'quality of life' and 'sexuality' (Appendix 6.2).

### **Hand search**

To ensure all research in this field was identified, an internet hand search was conducted via Google Scholar using combinations of the search terms 'prostate cancer', 'sexual orientation', 'gay', 'homosexual', 'cancer' and 'sexuality'.

### **Level of evidence**

As the eligibility criteria enabled both qualitative and quantitative data to be included in the systematic review, two classification scales were required, to determine the strength of evidence provided by each data type. Table 6.1 shows the classification scales.

Table 4.1 Hierarchy of Evidence: Classification scale used in the review of quantitative and qualitative research.

	Research Design/Types of Studies	
Classification	<b>Quantitative Research</b>	<b>Qualitative Research</b>
	Public Health Agency of Canada scale (21)	Daly scale (22)
Level I	Experimental design/ Randomised controlled trials	Generalisable studies
Level II	Quasi-experimental design. Controlled studies without random	Conceptual studies

	assignment but with control groups, comparison groups or counter-balanced design.	
Level III	Analytic observational study. Cohort studies, case control studies	Descriptive studies
Level IV	Not applicable	Single case studies

*Quantitative research:* The level of evidence provided by the quantitative papers was assigned using the three-tier classification scale of the Public Health Agency of Canada (21). For this scale, Level I provides the strongest level of evidence, while Level III indicates the weakest level. Each level of evidence is further divided into Limited, Moderate and Strong, for a more specific ranking.

The Public Health Agency of Canada has further sub-categories of each level of evidence (21). These are:

- limited (no supporting evidence from any published systematic review or meta-analysis)
- moderate (supporting evidence from at least one published systematic review or meta-analysis, with an appropriate target population and a moderate-to-high risk of bias)
- strong (supporting evidence from at least one published systematic review or meta-analysis, with an appropriate target population and a low risk of bias).

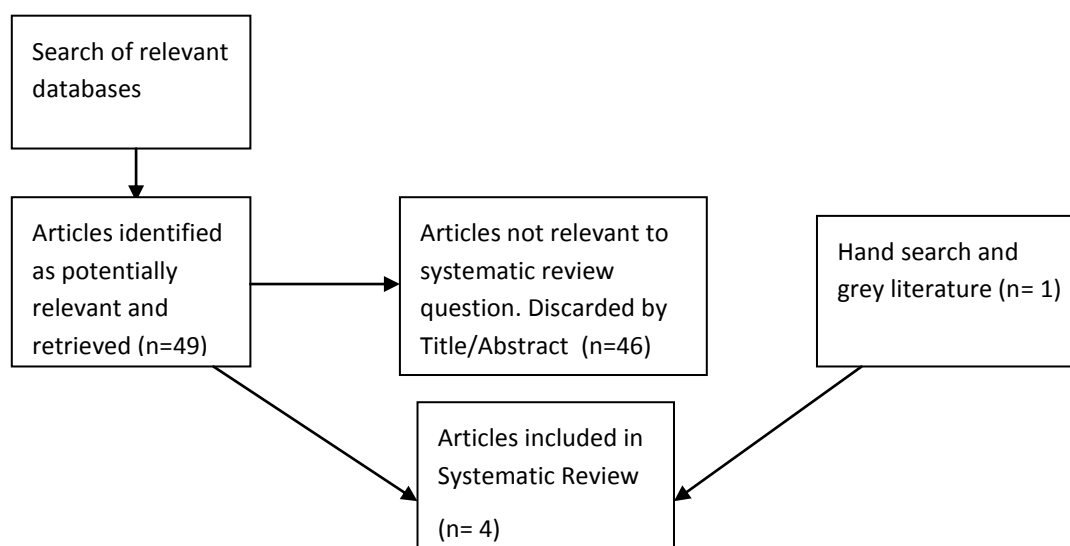
*Qualitative research:* The four-level classification system as outlined by Daly was used for the identified qualitative studies (22). This hierarchy classification allocates single case studies to Level IV the least likely to produce good evidence for practice. Descriptive studies—while providing helpful quotations, but failing to provide detailed analysis—were listed as Level III. The 'Descriptive studies' classification demonstrates that a phenomenon exists in a defined group (which in this review would refer to gay men); while the phenomenon for consideration would refer to issues surrounding mental health, quality of life and well-being. Conceptual studies where data analysis is in accordance with themes, yet limited by lack of sample diversity, were classified as Level II. Generalisable studies (Level I), accounting for all data in a diversified sample, present the best evidence for practice using this classification system.

## Results

### Study selection and characteristics

The search strategy yielded a total of 49 papers, once duplicates were eliminated. Of these papers, 46 were rejected as they did not comply with the inclusion criteria. Hand searching and grey literature produced one additional study. In total, four papers were retrieved for inclusion in the systematic review. Two of the selected papers used quantitative methods, while two were qualitative papers. The reference lists of the four papers were scanned yet provided no additional papers suitable for inclusion. Two studies used an online survey to source data (8, 23). One study employed face-to-face interviews with participants, and one study used an asynchronous online focus group to collect information (1, 24).

**Figure 4.1: Method of inclusion and exclusion of studies for the systematic review**



### Summary of identified studies

At the time of writing, this systematic review identified the study by Hart as one of only two quantitative works which investigated the impact of prostate cancer on the health-related quality of life (HRQoL) of gay men (8). This work compared the findings in terms of HRQoL with those of population norms. Gay men reported statistically worse functioning and more severe bother scores compared to norms on the Expanded Prostate Cancer Index (EPIC) urinary, bowel and hormonal symptom scales. EPIC sexual functioning scores and ejaculatory functioning scores were worse for gay men, compared to norms. Compared to men in other published research, this study found that gay men had a higher fear of cancer recurrence.

The study by Zhang investigated patient-reported treatment satisfaction as influenced by psychosocial and disease-related factors (23). Sixty-six self-identified gay and/or bisexual men diagnosed with prostate cancer were surveyed online to assess sexual function; satisfaction with healthcare; ejaculatory, urinary and bowel bother; sexual orientation outness level; illness intrusiveness; and amount of partner communication. This study indicated that communication was the most significant predictor of patient satisfaction in a sample of gay men.

In the small qualitative pilot study by Filiault, two gay men with prostate cancer and the partner of a gay man with prostate cancer were interviewed in depth (24). Filiault proposed that while the study relied on only three participants, such a qualitative work was able to delve more deeply than would otherwise be possible in a study with a larger participant pool. This work suggests that changes and strains in relationships, altered sexual function, altered gay identity and perception of the hetero-normative attitudes in the health system all impact on gay men's experiences of prostate cancer (24).

The work by Thomas showed that psychosocial aspects of prostate cancer, which included altered sexual identity, changed sexual relationships and interaction with the health care community, were particularly problematic for gay men (1). The privacy provided by the online nature of the investigation was an important issue for this group. The results of this research indicated that further quantitative studies concerning measures of HRQoL are required, with the expectation that a true measure of HRQoL difference will be evident by the involvement of separate cohorts of gay and straight men, with and without a diagnosis of prostate cancer. Table 6.2 summarises the key findings of each study.

**Table 6.2: Descriptive summary of systematic review papers**

Paper	Study type, method & data extraction category	Study aim / description	Participants	Findings	Level of evidence
Hart (9)	Quantitative, online survey, database (journal)	Cross-sectional internet based survey. Functioning and bother scores compared with those of norms in the domains of urinary, bowel and hormonal symptoms. Sexual, ejaculatory, mental health and physical health functioning assessed.	n= 92 (Gay)	Gay men may be particularly vulnerable to decrements in health-related quality of life (HRQoL) after prostate cancer treatment.  Compared study results with population norms.	Level III (limited)
Zhang (23)	Quantitative,online survey, database (journal)	Sexual function, satisfaction with healthcare, ejaculatory, urinary and bowel bother assessed. Sexual orientation outness level, illness intrusiveness and amount of partner communication assessed.	n = 66 (Gay or bisexual)	For gay men, patient satisfaction predicted by communication.  Potential benefits of interventions addressing relationship factors, specifically communication.	Level III (limited)
Filiault (24)	Qualitative, interview, database (journal)	Pilot study to examine the experiences, frustrations and perspectives of gay men diagnosed with prostate cancer.	n=3 (Gay)	Participants experienced relationship changes.  Altered sexual function and associated implications for gay identity.  Hetero-normative attitudes problematic.	Level III
Thomas (1)	Qualitative asynchronous focus group, grey literature, (journal)	Online pilot study to determine the concerns of gay and bisexual men diagnosed with prostate cancer	n=10 (9 gay, 1 bisexual)	Significant psychological impact of prostate cancer diagnosis highlighted.  Degree of distress was associated with extent of side effects and availability of support systems.	Level III

## Level of evidence

Table 6.2 above shows that for the two quantitative studies included in the systematic review, the level of evidence provided by each study was classified as Level III (limited) (8, 23). The two qualitative studies were also classified as Level III (Descriptive studies) evidence (1, 24).

**Table 6.3: Study themes identified**

Study	Health-related quality of life	Communication	Relationship concerns	Gay identity	Sexual functioning	Psychological impact
Hart	✓				✓	
Zhang	✓	✓			✓	
Filiault		✓	✓	✓	✓	✓
Thomas		✓	✓	✓	✓	✓

### **Quality of life (QoL)**

Two studies were identified which addressed the theme of QoL (8, 23). The research by Hart indicated that gay men reported statistically significantly worse functioning and more severe bother associated with urinary, bowel and hormonal symptom scales, compared with figures taken from the general population (8). Gay men also reported worse sexual functioning scores, worse ejaculatory functioning scores and significantly worse mental health functioning than norms. Moreover, gay men reported significantly higher fear of cancer recurrence. While sexual bother scores and physical functioning for gay men were not significantly worse than for those of the norms, the QoL of gay men was more at risk of decrease, compared with the published figures from the general male population (8). Further to this, the study by Zhang which investigated predictors of patient-reported satisfaction indicated that lower bowel bother predicted higher satisfaction with prostate cancer care (23).

### **Communication**

Three studies identified communication as an important factor which contributed to the experiences of gay men with prostate cancer. Two of these studies suggested that communication regarding both the health care system and associated hetero-normative attitudes could present problems for gay men diagnosed with prostate cancer (1, 24). The

third study in this group indicated that greater frequency of patient-partner communication predicted higher satisfaction with prostate cancer care (23). This study suggested that addressing relationship factors—principally communication—is potentially beneficial regarding prostate cancer treatment of gay men.

### **Relationship concerns**

Relationship issues were highlighted in two studies as being an area of particular concern for participants (1, 24). The study by Filiault cited relationship concerns as an area where change, particularly regarding the ambiguous role of partners in treatment and recovery, was likely, following a prostate cancer diagnosis. As is the case for heterosexual couples, where the diagnosis of prostate cancer impacts on the female partner, so too does such a diagnosis affect the partner in a gay relationship (24). Filiault suggested the health care system should provide support for the partners of the gay men diagnosed with prostate cancer, in the same way that provision is now being given to the female partners of heterosexual men.

### **Gay identity**

Two studies indicated that gay identity would be impacted by prostate cancer (1, 24). The study by Filiault suggested that for gay men diagnosed with prostate cancer, interaction with other gay men, particularly in a sexual context, is altered. This research suggested that following diagnosis, a sense of self and body image are compromised. The removal of the prostate—a site of unique significance in the sexual repertoire of many gay men—ensured that a sense of sexuality was irrevocably altered (24). Diminished sexual function was associated with altered gay identity (24). The online focus group by Thomas noted an inability to achieve intimacy and a failure of spontaneity in sexual encounters as important issues following prostate cancer treatment in a cohort of gay men (1). Such altered sexuality was reflected in an altered sense of gay identity.

### **Sexual functioning**

Sexual functioning was an area of particular concern for gay men and was a focus in all four papers presented in the review (1, 8, 23, 24). In the study by Hart, gay men reported worse Expanded prostate cancer index composite (EPIC) sexual functioning than population norms (8). Research has shown that patient satisfaction following prostate cancer intervention is influenced by sexual function outcomes (23). Such altered sexual functioning was an important issue for those in the online focus group (1). The inability to gain an erection post-

prostate cancer surgery, reduced penile length and absence of ejaculate at orgasm were all seen as particularly troublesome in the repertoire and setting of gay sexual encounters (1).

### **Psychological impact**

Altered sexual identity and relationships, together with difficulties associated with health care community interaction, were significant factors contributing to the psychological impact of prostate cancer (1). The fear of a judgemental attitude by the treating doctors following a disclosure of sexual orientation (24) was seen as a factor contributing to the psychological implications following a prostate cancer diagnosis (24).

### **Discussion**

Researchers have suggested that gay identity and gay sexual practice make the experience of this group of men different from that of straight men (4, 6, 12, 25-27). While acknowledging the differences between the gay and straight groups, such papers were omitted from the review as only those that directly explored the experiences of gay men with prostate cancer were included.

The extensive review of the literature identified only four studies which were categorised Level III quality or below (Level I studies being of the highest quality).

The paucity of studies of gay men and a prostate cancer diagnosis may have resulted from the difficulty in accessing this often-hidden group of men, lack of research funding, or publication bias as reports concerned with gay men's health may be deemed of no interest to the readership. Personal factors may also contribute to the difficulty of engaging gay men with prostate cancer into research. It may partly be because gay men diagnosed with prostate cancer are older and do not want to disclose their sexual orientation due to the fact that in their youth, homosexuality was a criminal offence, and disclosure carried major consequences. More liberal and relaxed community attitudes in Australia today, as well as decriminalisation of homosexual sex, now enables research into prostate cancer and sexual orientation to proceed, albeit belatedly.

The papers presented in this systematic review suggest that the diagnosis of prostate cancer affects the health and quality of life of gay men. Unfortunately the evidence provided is not sufficiently strong to form a basis for decision making, or for policy generation and further research is indicated.



While Level I evidence (generalisable studies or experimental design) may be difficult, given the nature of prostate cancer, this current review indicates that future research should be of sufficient quality to improve upon that which currently exists.

This review strengthens the argument for the routine collection of sexual orientation data in all further prostate cancer studies. Ideally these studies should be prospective and of large sample size.

### **Summary and conclusion**

While the evidence presented suggests that sexual orientation has a role in determining quality of life in relation to prostate cancer, further research is required to clarify this role more fully. Any quality of life differences detected would suggest that counselling at the time of diagnosis ought be tailored accordingly, thereby ensuring the best possible outcomes for all men in the trajectory of prostate cancer, regardless of sexual orientation.

Although only four papers were found to be suitable for inclusion in the review, this was sufficient number to enable emerging themes to be identified. Health related quality of life, communication issues, health concerns, relationship concerns, gay identity, sexual functioning and psychological impact were identified as areas of concern in the quality of life of gay men diagnosed with prostate cancer.

The findings of the systematic review guided the development of the focus group study presented in Chapter 7 and the internet based cross sectional study presented in Chapter 8.

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## Appendix 6.1

<http://www.caul.edu.au/caul-programs/research/repository-services/repository-manager-tools>

(accessed 10-9-14)

1. Repositories reviewed:

2. Bond University [e-publications@bond](#) ,

3. Edith Cowan University [Research Online @ ECU](#)

- Southern Cross University [ePublications@SCU](#),

- University of Notre Dame [Research Online @ ND](#)

4. University of Wollongong [Research Online](#),

5. Charles Sturt University [CSU Research Output](#)

6. Curtin University of Technology [espace@Curtin](#) ,

7. Australian Catholic University [ACU Research Bank](#)

- University of Melbourne [University of Melbourne ePrints Repository \(UMER\)](#)

- University of South Australia [UniSA Research Archive](#)

- University of Western Australia [UWA Research Repository](#),

- Australian National University [ANU Research Repository](#),

- Flinders University [Flinders Academic Commons \(FAC\)](#),

- Griffith University [Griffith Research Online](#),

- University of Adelaide [Adelaide Research & Scholarship](#),

- University of Sydney [Sydney eScholarship Repository](#),

- Auckland University of Technology [AUT Scholarly Commons](#),

- Massey University [Massey Research Online](#),

- University of Auckland [Research Space@Auckland](#),
- University of Canterbury [University of Canterbury Research Repository](#),
- University of Otago [Otago University Research Archive](#)
- University of Waikato [Waikato Research Commons](#)
- 8. Victoria University of Wellington [Research Archive](#)
- 9. James Cook University [ResearchOnline@JCU](#)
- Murdoch University [Murdoch Research Repository](#)
- Queensland University of Technology [QUT ePrints](#)
- University of Southern Queensland [USQ ePrints](#)
- University of Tasmania [UTAS ePrints](#)
- Victoria University [Victoria University Institutional Repository \(VUIR\)](#)
- University of Canberra [UC Research Repository](#)
- University of New South Wales [UNSWorks](#)
- Deakin University [Deakin Research Online](#)
- RMIT University [Research Repository](#)
- University of Queensland [UQ eSpace](#)
- 10. CQUniversity [aCQUIRe](#)
- LaTrobe University [LaTrobe University Institutional Research Repository](#)
- Macquarie University [Macquarie University ResearchOnline](#)
- Monash University [ARROW Repository](#)
- Swinburne University of Technology [Swinburne Research Bank](#)
- University of Ballarat [UB Research Online](#)

- University of New England e-publications @ UNE
- University of Newcastle NOVA
- University of the Sunshine Coast USC Research Bank ,
- University of Western Sydney UWS Research Repository

## Appendix 6.2

The following sites were accessed on 6/12/12 using combinations of the following search terms: Prostate cancer, sexual orientation, gay, homosexual, cancer, sexuality

- National Library of Australia Australian Theses in Trove  
<http://trove.nla.gov.au/book?q=&l-format=Thesis&l-australian=y>
- BritishLibrary EThOSBeta <http://ethos.bl.uk/Home.do>
- Networked digital library of theses and dissertations  
<http://www.ndltd.org/serviceproviders/scirus-etd-search>
- ProQuest Dissertations and Theses Full Text  
<http://www.lib.latrobe.edu.au/databases/terms.php?I=ARL77782>
- ProQuest Dissertations & Theses: UK & Ireland  
<http://www.lib.latrobe.edu.au/databases/terms.php?I=ARL77850>
- ThesesCanada <http://amicus.nlc-bnc.ca/s4-bin/Main/BasicSearch?coll=18&l=0&v=1>
- Theses (Informit)  
<http://www.lib.latrobe.edu.au/databases/terms.php?I=ARL17297>



## **Chapter 7: Online Focus Group Study**

Below is a published paper called “*The experiences of gay and bisexual men diagnosed with prostate cancer: results from an on-line focus group*” which has been peer-reviewed and was published in the European Journal of Cancer Care in 2013.

## The experiences of gay and bisexual men diagnosed with prostate cancer: results from an online focus group

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THOMAS C., WOOTTEN A. & ROBINSON P. (2013) *European Journal of Cancer Care* 22, 522–529  
The experiences of gay and bisexual men diagnosed with prostate cancer: results from an online focus group

Research concerning gay and bisexual men diagnosed with prostate cancer is sparse. An online focus group was conducted over a 4-week period with participants responding to a range of discussion questions concerning their experiences following a prostate cancer diagnosis. Emerging themes were identified and consensus reached. A summary of each of the themes was produced which the coders agreed conveyed the essence of the online discussion. All men who took part in the online focus group reported that prostate cancer significantly impacted their lives. Unexpectedly, some participants actually gained a positive perspective and adopted a sense of empowerment. Participants spoke about emotional responses to a diagnosis of prostate cancer, accessing help and support, the impact of incontinence, the impact of sexual changes on identity, a re-evaluation of life, changed sexual relationships, the need to find the most suitable healthcare professionals and identification of current needs to improve quality of care. These areas of disquiet suggest that the psychological impact of this disease may be quite significant over an extended time-frame. Further research needs to be undertaken to assess the degree of distress accompanying the treatment of gay and bisexual men with prostate cancer.

**Keywords:** gay, bisexual, focus group, prostate cancer, stigma.

### INTRODUCTION

Prostate cancer is the most common type of newly diagnosed cancer (excluding basal and squamous cell carcinomas) in men, with over 20 000 new cases in Australia in 2008 (Australian Institute of Health and Welfare 2012). Researchers have shown that the number of gay (homosexual) men in the Australian population is between 1.6% and 2.5% (Smith *et al.* 2003; Prestage *et al.* 2008). As a high percentage of men with prostate cancer live for

greater than 5 years following diagnosis, approximately 2000 gay Australian men are estimated to be currently living with a diagnosis of prostate cancer. However, there are very few studies of gay and bisexual men who have been diagnosed with prostate cancer (Blank 2005).

Prostate cancer is usually diagnosed in older men, raising particular issues for older gay men. Issues of stigma and marginalisation are significant for many of these men who have lived the major, formative periods of their lives in a time when homosexual acts were criminalised and homosexuals stigmatised (Mitteldorf 2005; Blank *et al.* 2009). Mitteldorf (2005) suggests that coming out as a prostate cancer patient, 'with a fear of being dismissed or minimised, has distinct parallels to coming out as a gay man, with fears of rejection' [p. 63]. The ongoing desire for privacy and confidentiality of these men may create

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unique barriers to their health care with men reluctant to divulge personal information to their doctors (Thompson 2004).

Previous research has indicated that common discussion points on a web-based forum targeted towards gay men with prostate cancer included the loss of sexual function and issues concerning psychosocial support (Thomas 2012).

An Australian population study found that homosexually (gay) active men have a greater likelihood of depression than do heterosexual (straight) men (Corboz *et al.* 2008). However, to date there has been little published work regarding how male sexuality influences health-related quality of life (HRQOL) following a diagnosis of prostate cancer. The work by Hart *et al.* one of the few contemporary studies available, suggests that gay men may be particularly vulnerable to decrements in HRQOL after prostate cancer treatment compared with that of a similarly matched male cohort of the general population of undisclosed sexual orientation (Hart *et al.* 2011). However, an earlier Swedish study by Eriksson *et al.* reported that gay men, without a diagnosis of prostate cancer, have a lower psychosocial HRQOL than the general male population (Eriksson & Berglund 2007). Therefore, in the research by Hart it is unknown as to what extent the decrease in HRQOL was related to either the presence of prostate cancer or identifying as gay. These two studies are particularly important in that they highlight the difficulty of determining the extent of influence of a prostate cancer diagnosis on the HRQOL of the gay population.

Research suggests that while gay and straight men might share many of the same concerns regarding prostate cancer, the priorities and meanings assigned to such concerns may differ (Thomas 2012). Smith suggests further that there may be some concerns that are unique to gay men (Smith *et al.* 2007). Those issues might include whether it is possible to engage in penetrative anal sex after prostate surgery, homophobia and/or disregard to sexuality when being diagnosed or treated for prostate cancer, the hetero-centric nature of the medical profession and the impact of polygamous (open) relationships (Blank 2005; Blank *et al.* 2009). While these issues are important and will undoubtedly influence HRQOL outcomes, this current study seeks to use a qualitative methodology to explore the unique experiences of gay and bisexual men with prostate cancer.

This study was therefore designed to qualitatively identify the experiences, concerns and perceived information needs of gay and bisexual Australian men diagnosed with prostate cancer.

## METHODS

### Theoretical considerations

Stigma theory is used as the theoretical framework for this study (Goffman 1963). While sexual orientation and prostate cancer are concealable stigmas, recent research has shown that individuals who choose to hide such a stigma face considerable stressors and psychological challenges as the threat of discovery and the difficulty of some social situations create a difficult predicament (Pachankis 2007).

### Participants

Eligible participants were Australian men who self-identified as gay or bisexual having had a diagnosis of prostate cancer within the last 7 years. Participants must have had an ability to read English without translation. Previous treatment for prostate cancer was not a prerequisite for eligibility for admission to the focus group. The participants were recruited by word of mouth through prostate cancer support groups for gay and bisexual men. Participants fulfilling the criteria for admission to the focus group contacted the group researcher, provided consent to participate and provided basic demographic details prior to the focus group.

### Procedure

The use of a focus group in this study was chosen in order to elicit common perceptions, views and a range of opinions. This method of research is used to encourage self-disclosure among participants (Wilson 1997). The employment of the focus group, which delves into the cancer experience of the participants, allowed for the development of a broad and deep understanding regarding the issues of concern, rather than a quantitative summary. This methodology was felt to be the most engaging for this population as previous research has indicated that recruitment of gay and bisexual men to research has been challenging. This methodology allowed participants to engage in the study via an anonymous platform (online) while at the same time offering the opportunity to share experiences and opinions with others. Access to the focus group was via an online forum attached to the Cancer Council Victoria website (<http://www.cancervic.org.au/forums>). The focus group was conducted across a 4-week period and was accessed by each participant using his own unique password supplied via the investigator. The asynchronous nature of the online focus group enabled participant postings to be completed at any time. The format of this study

gave participants the opportunity to discuss their common experiences and build on one another's comments.

#### Data collection

Prior to commencement of the focus group all participants completed a demographic questionnaire which included a self-report on primary treatment. The online focus group ran for a period of 4 weeks. During this period, the forum moderator posted a series of structured questions which aimed to encourage participants to identify those issues which were of particular concern to them in their experience of prostate cancer. These responses were elicited by a number of questions relating to prostate cancer being posted on the website forum.

The initial question, 'How did the diagnosis of prostate cancer initially affect you?', was introduced at the commencement of the study by the forum moderator. This was followed by new questions at regular intervals over the 4-week period or when a saturation of ideas concerning a particular question had occurred. During the course of the study, participants were regularly encouraged to engage with the particular prostate cancer issue at hand. At the conclusion of the study, a complete transcript of all postings was printed from the website for review.

#### Data review

The transcripts of all responses were examined independently by the three researchers and a coding system was used to code into themes. Emerging themes were identified and consensus reached between the three coders via consultation. A summary of each of the themes was produced which the coders agreed conveyed the essence of the online discussion.

The study was approved by the human research ethics committee of La Trobe University, Melbourne, Australia.

## RESULTS

The demographic characteristics of the focus group are shown below in Table 1.

The average time from diagnosis to primary treatment was 3 months. The average time from diagnosis to participation in this focus group study was 26 months (range from 3 to 54 months post diagnosis).

Of the nine participants who had undergone treatment, 7 had a radical prostatectomy while the remaining 2 had undergone radiation treatment followed at a later time by androgen deprivation therapy. Pseudonyms have been applied to participants of the focus group to ensure confidentiality.

**Table 1.** Demographic characteristics of focus group ( $n = 10$ )

Sexual orientation	
Gay	9
Bisexual	1
Age (years)	
Mean	59.9 (range 47–70 years)
SD	6.9
Prostate-specific antigen at diagnosis	11.2 (range 4–49)
Primary treatment	
Prostatectomy	7
Radiation therapy	2
Active surveillance	1
Household income, average	AU\$50 000
Education level	
Postgraduate	2
Graduate	2
Trade school	2
High school	4
Ethnicity	
'Anglo'	1
'Anglo-Celtic'	6
'Caucasian'	3
Partnered (male)	2
Un-partnered	8
First language	
English	10
Residence	
Australian capital city (total)	10
Sydney	7
Melbourne	3

Data analysis from the focus group transcripts identified 8 key themes. The thematic summary is presented below.

#### Emotional response to prostate cancer diagnosis

Focus group participants discussed a range of emotional responses to the diagnosis of prostate cancer. These included shock and disbelief, the need to confront ones own mortality and the need for information:

My first reaction was to question my remaining time on earth. (Jeff, age 60)

Five participants were diagnosed promptly following a rise in prostate-specific antigen (PSA). Considerable delay between the initial blood test and an actual diagnosis was experienced by two other participants. These participants spoke about the psychological burden of such a delay.

Assessing information was also challenging for participants as information had to be gained quickly at the time of diagnosis when the psychological impact of the diagnosis was being shouldered.

#### Accessing help and support

The majority of the focus group participants were non-partnered and most indicated that close family and friends



were the main source of help and support at the time of diagnosis and treatment. Three participants felt that a support group for gay and bisexual men might provide a safe haven for expressions of comfort in this time of crisis; however they noted that such a support group was not available in their geographical area.

Three participants identified an inner strength which was called upon to meet the challenges of prostate cancer.

Four participants responded with a positive perspective to the prostate cancer diagnosis accompanied by a sense of empowerment at being able to gain an insight into that which was actually important and worthwhile in their lives:

... letting go of attachment to many outcomes and processes. (William, age 47)

Two participants regarded an ability to grieve and a capacity to share such grief with those giving help and support as particularly important:

... it needs to be absolutely fine to grieve- to cry, to get angry, to feel lousy. (William, age 47)

#### Impact of incontinence

For one participant, daily social interaction and routine domestic issues were problematic due to incontinence:

... (because of incontinence) going to the supermarket is a struggle. (Michael, age 66)

The side effect of incontinence remained a problem for two participants long after treatment completion. Such an outcome left one of these participants in particular, with a sense of regret concerning the treatment which was undertaken:

...but I do so wish things had been different. (Stephen, age 62)

#### Impact of sexual changes on identity.

For the majority of participants, loss of erectile function, decreased penile length and resulting altered sexual function impacted on a sense of masculine identity. The loss of spontaneity of sex was seen to be an important issue. One participant felt that the burden of prostate cancer diagnosis and treatment was increased by his inability to engage sexually with his partner resulting in less intimacy in their relationship. A participant undertaking androgen deprivation therapy as a secondary form of treatment felt that his male identity had been altered markedly. As well as having great issue with anxiety and mood fluctuations

this patient thought of himself as experiencing female menopause in a male body. Another participant claimed that his treatment resulted in his questioning his own self worth as a man both physically and mentally. Altered gay sexual practice became an identity issue for one participant who had to change from being an insertive (top) to receptive (bottom) partner due to erectile dysfunction.

#### Emotional state moderated by ability to re-evaluate life

Differences were seen within the group regarding a perception of the experience of prostate cancer. Of the seven participants who posted comments on this topic, five were able to frame their experiences with positive outcomes while two others focused on the negative outcomes of their prostate cancer experience. One participant who spoke about positive outcomes thought his experience had a positive impact in that he was able to advise friends on the need and value of PSA testing. Over half the participants found a new appreciation for living in the 'Now' and expressed an appreciation of the love and support of those close to them.

There was a re-evaluation as to what was really important in the lives of a number of these men. They were able to let go of issues they deemed to be trivial. Some found meditation was helpful in coming to terms with their new health status. One participant felt 'that life is too valuable to be wasted' and had found a 'huge sense of peace'. (Brad, age 53)

One participant failed to see any positive aspects in the whole experience, while another expressed regret and longed to return to his life before the diagnosis of prostate cancer:

... it's hard really to get a positive out of being transformed from a fit, healthy, happy life loving (man) ... (to) a changed being who is depressed, full of stress and a lot of anxiety. (Stewart, age 57)

#### Changed sexual relationships

Erectile dysfunction, loss of ejaculation and loss of libido were problems for most participants. Such dysfunction resulted in the loss of spontaneous sex, altered sexual practice and performance anxiety.

Following a diagnosis, the majority of the participants reported that they no longer felt able to engage in intimacy nor were they able to be spontaneous in their sexual encounters. The loss of intimacy, fear of rejection and perceived emotional gap made the long-term prospects of relationships look bleak. Reluctance to engage in new

sexual encounters was a common thread in the discussion. This was shown by one participant who felt hesitant to seek a new partner since he perceived himself to be undesirable in the gay world:

... feel (like) "damaged goods" reluctant to really get myself out there. (Stewart, age 57)

However, one participant suggested that a move away from the phallic focus of gay sex and exploration of alternative ways of expressing sexual intimacy had helped him:

(I see) ... the cancer legacy as an opportunity to reframe my sense of my sexuality and my sense of being a gay man into a different approach. (William, age 47)

#### Finding the right healthcare professional

There was a general disquiet concerning the attitudes of urologists. A number of men transferred themselves to other specialists. Participants stated that it was not necessarily a 'gay friendly' specialist they were looking for, but rather that warmth and sincerity were traits to be sought in choosing a urologist compared with dismissive attitudes which were considered to be particularly unhelpful.

In marked contrast to the perception of the urologists, most participants were satisfied with the role of their general practitioner (GP) in the prostate cancer journey. The local GPs, whether gay or straight, were thought to be empathetic to the experiences of the participants. Most participants expressed that they had consciously sought out the right GP for them:

... except for the empathy of my nice GP, no other professionals will address this issue (penile shortening). I get the impression it's no big deal. Hey, it is to me! (Luke, age 60)

#### Current needs to improve quality of care

Participants felt that the emotional needs of both gay and straight men are not being adequately addressed by all medical practitioners and that there was a need for a structured plan detailing care and support to be shared between health professionals and the patients themselves.

Communication with urologists, which was seen as extremely problematic, was a continuing thread throughout the online postings. Participants spoke about urologists often failing to outline the potential side effects of proposed treatments or discussing the possible psycho-

logical impact of such treatments. The conservative hetero-normative and sometimes homophobic nature of those involved in the medical process of prostate cancer resulted in distress, dissatisfaction and negative psychological impact for participants:

... we need to have urologists clued up to deal with gay men, we need understanding that our needs and issues are not the same as (those of) a heterosexual man. (Brad, age 53)

The majority of men felt that web based information was directed at men over 60 years of age. It was suggested that support groups specifically for gay and bisexual men would be of benefit in coping with this cancer. Those who had attended such groups felt that they were most helpful.

Participants felt that all aspects of care regarding sexual needs, medical practice, relationships and provision of support for gay and bisexual men must be dealt with sensitivity and respect.

Failure to provide any form of ongoing support post treatment was seen as an area where immediate improvement could be made. Participants stated that a 'care-plan' should be implemented to address the current inadequacies. Although resources to implement the plan were seen as problematic, it was felt that change in this area could be driven by the gay community.

#### Experiences of taking part in the online focus group

A number of participants felt that they had learnt from hearing the experiences of other gay and bisexual men in regard to prostate cancer. The participants were pleased at being able to have an opportunity to air their 'feelings, thoughts and frustrations':

... the whole exercise has proved beneficial and cathartic. (Colin, age 70)

A hope was expressed that an ongoing, safe, empowering discussion forum for gay and bisexual men diagnosed with prostate cancer could be established within Australia.

One participant expressed the idea that the health issues relating to men, regardless of sexual orientation, should be dealt with openly and that services be made available to address ongoing psychological aspects of prostate cancer.

#### DISCUSSION

Stigma theory presents a useful lens for examining the many facets of prostate cancer diagnosis and treatment

allowing data to be examined in depth (Dovidio *et al.* 2000; Gray *et al.* 2000; Link & Phelan 2006; Else-Quest *et al.* 2009). Stigma is a social issue which, together with minority status and discrimination, intersects with prostate cancer (Perlman & Drescher 2005). Perceived stigma associated with prostate cancer may result in the failure of disclosing a diagnosis and as such acts as an impediment to health promotion (Corrigan 2004). A perceived constant threat of stigmatisation, as might occur in respect to prostate cancer, leaves a man exposed to the possibility of chronic stress (Link & Phelan 2006).

While participants experienced a range of emotional responses to their diagnosis of prostate cancer with difficulties encountered regarding choice of treatment and consideration of associated side effects, an underlying sense of stigma was apparent.

Additionally, a sense of regret was sometimes registered when a chosen treatment failed to fulfil the participant's expectations regardless of whether such expectations were realistic or otherwise. Although the online study has shown that help and support during the time of prostate cancer diagnosis and treatment has come mainly from family and friends, there are some who have undertaken the entire prostate cancer journey alone. The men in this latter category felt that family and friends were not available to help or they simply did not want to be a burden to others.

Erectile dysfunction, loss of ejaculation, loss of penile length, incontinence and loss of libido were particularly problematic and were accompanied by stigma. This overall sexual dysfunction resulted in a number of these men thinking that they were 'damaged goods' incapable of future relationships. Such self-perceptions of stigma made it difficult to move forward past the idea of being a person diagnosed with prostate cancer to one who has survived the disease.

In a further display of stigma, some men saw themselves as sexually undesirable as a result of their sexual difficulties and therefore unable to engage in any forms of intimacy. This experience may have been heightened by the fact that the majority of participants in the focus group did not have intimate partners. It is possible that this resulted in a much lower level of perceived support, quite in contrast to the literature detailing the experiences of heterosexual men.

While sexual dysfunction bestows an invisible stigma in that it is unseen by the general public, such a clandestine nature may actually help some men cope with diminished self-esteem and confidence (Goffman 1963).

Participants who adopted a pragmatic approach to the reality of the situation experienced a more positive emo-

tional impact to their prostate cancer experience. The researchers found such a positive outlook to be a surprising result given the possible range of side effects from prostate cancer treatment. However, such a result was in keeping with the work of Roesch *et al.* who suggested that 'active approaches to coping with prostate cancer are beneficial psychologically (and) physically' (Roesch *et al.* 2005). The emotional impact was also influenced by each participant's perception of his own masculinity regarded both in a hegemonic sense and within the gay and bisexual sphere. This altered perception of masculinity added to the impression that future relationships were highly unlikely. Such a view suggested that the participant may have adopted an internalised stigma in relation to the outcomes of prostate cancer treatment. This must be considered in the light of the possibility of the existence of concurrent stigma associated with sexual orientation.

The postings of the focus group indicate that the GPs treated these men with a sense of respect, dignity and understanding. However, while sensitivity and compassion were not always evident in encounters with urologists, the dismissive attitudes of such providers were found to be no longer acceptable nor tolerable.

Participants reported that preparation for the experience of side effects was not adequate and that further information from specialists was important in coping with these experiences. Information and education should be provided concerning both prostate cancer and the likely outcomes of available treatments should be available to gay and bisexual men, including details of penile shortening, loss of ejaculate and loss of erectile functioning or libido. Such information would assist men to negotiate these experiences with full awareness and might reduce the psychological distress experienced. The need to tailor specific information regarding all aspects of post-treatment sexual function as might apply to the sexual repertoire of gay and bisexual men, in particular anal intercourse and the issues encountered by men in open relationships is also indicated by these data.

In order to develop a more effective strategy to address prostate cancer survivorship, urologists and other specialists involved with this group of men must be encouraged to provide individual care plans. None of the participants in this study received such a plan from their urologist and voiced a sense of abandonment once the particular treatment had ended. Participants of the focus group expressed concern that although treatment had concluded, many of the side effects (erectile dysfunction and incontinence) had lasted many years and could remain for a lifetime. The absence of assistance in dealing with these iatrogenic side effects is particularly problematic to these men. A



care plan would ideally be developed in consultation with the primary care provider who will also monitor other often complex medical and psychosocial needs (Grunfeld *et al.* 2011). The primary care provider is pivotal in this strategy as the urology resources are in scarce supply (Shulman *et al.* 2009).

It is anticipated that examination of the prostate cancer experiences of gay and bisexual men will encourage health professionals to have a greater understanding of the issues confronting this group of men thereby ensuring improved outcomes and improved support.

### Strengths and limitations

The main strength of this study was the use of online technology which enabled the researchers to gain access to a group which has previously been difficult to engage. As the focus group was conducted over a 4-week period it also permitted participants to revisit particular subjects at any time during the duration of the study.

A limitation of this study concerns time lapse. The mean time from diagnosis until the commencement of the study was 26 weeks. Accurate recall of such a past event may not be possible. Although, it might equally be argued that the diagnosis of prostate cancer is such a significant life-changing event that many are able to recall all matters

in this regard with precise detail regardless of the time since diagnosis.

A further limitation of the study is the cross-sectional design. The concerns of these men may have altered with time and this study is limited by its methodology in uncovering this.

Furthermore, the self-selection of the 10 participants into the focus group may have introduced a selection bias into the study.

### CONCLUSIONS

This study indicates that there are a number of areas of concern regarding the trajectory of prostate cancer for gay and bisexual men. These areas of disquiet include: the emotional response to a prostate cancer diagnosis, access to help and support, the impact of incontinence, the impact of sexual changes on identity, the ability to re-evaluate life, changed sexual relationships, finding the right healthcare professional, resulting issues from aspects of stigma and the ability to improve quality of care by assessing current needs.

Further research needs to be undertaken to assess the degree of distress accompanying the treatment of gay and bisexual men with prostate cancer and interventions to improve outcomes in this often under-served population.

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## **Chapter 8a: Recruitment methods for the Quantitative study**

The aim of the quantitative study was to investigate the impact of a prostate cancer diagnosis on the body image and self-esteem of gay and straight men.

A particularly interesting aspect of this study concerned the “generalisability” of the recruitment strategy which is addressed below.

Complex multi-faceted recruitment strategies for the second phase questionnaire based study.

In 2014 the use of an online survey to collect data is not unusual (25). The issue which remains problematic concerns the mode by which potential respondents are invited to complete a survey (26).

This is of particular concern when data are required from a population which is hidden or difficult to access (20). Such was the case in the recent study to investigate the impact of prostate cancer diagnosis and treatment with regard to sexual orientation.

A two-fold difficulty existed with the group of respondents required for this study:

- Issues regarding an altered sense of masculine identity following a prostate cancer diagnosis may have dissuaded potential respondents from survey completion.
- The survey required respondents to self-identify his sexual orientation. As men with prostate cancer are usually of more mature years (>50 years), the question of sexual orientation may have been problematic for gay (homosexual) men who may wish to continue to conceal their sexual orientation because of past challenges encountered in the heterocentric (i.e. heterosexually focused) medical arena.

Several approaches were used to maximise the possibility of potential recruits receiving an invitation to participate. The researcher emailed a private email list of friends and colleagues with an invitation to participate in the study and to pass the email on to as many friends as possible. The email contained a link to complete the survey. The researcher’s Facebook page was also used to invite study participation.

Once the eligibility criteria of being 30 years of age or older, male and living in Australia, were met, respondents were required to complete a survey using the online platform “Survey Monkey”. As well as an enquiry into the self-reported sexual orientation of each respondent,

the survey required answers to many intimate questions concerning self-esteem, body image, sexual function and urinary function in relation to a prostate cancer diagnosis.

For example:

- How big a problem has sexual function been in the last 4 weeks?
- How would you describe the frequency of your erections during the last 4 weeks?

Despite the nature of these questions, 834 eligible men responded.

Only the recruitment rate of the method “e-mail from study co-ordinator” can be calculated with certainty. There were 118 direct responses were received from 168 e-mails sent initially by the study co-ordinator. (Recruitment rate of approximately 72%). The recruitment rates of all other methods are unknown. Enquiries to email respondents suggest that emails were sent to approximately ten people requesting study participation. Therefore a “guesstimate” of the number of people contacted by e-mail via a friend is about 1680, providing a recruitment rate of approximately 24%.  $\{(407/(168 \times 10)) \times 100 = 24.2\}$

Comparing the “e-mail from the study co-ordinator” and “e-mail from a friend”, the former was more successful in terms of recruitment rate although the later achieved a higher number of responders.

The difficulty with using electronic means to recruit to studies is one of representativeness of responders, and lists are unlikely to be representative of a very specific population. However the email contact list of the study co-ordinator was able to access a large number of responses from gay men, the focus of this particular study. The result is shown in Table 9.1 with 31% of the study population self-identifying as gay compared with the 2% of the Australian male population (17). The self-identified sexuality of the study population is skewed compared with that of the general population yet this was a favourable outcome as the aim of the study was to investigate gay men with a diagnosis of prostate cancer. Accordingly, such a means permitted a large group of gay men to be accessed and then further classified according to prostate cancer diagnosis status. However, this group of responders cannot be claimed to represent the entire Australian adult male population without careful evaluation of their demographic characteristics against known population parameters.

**Table 9.1: Respondent characteristics**

Recruitment method and sexual identity	Self-identified sexual orientation of responders					Potential number of responders	Recruitment rate of responders
	Straight	Gay	Bisexual	Trans-gender/ Other	Total number of responders		
e-mail from study co-ordinator	72 (8.6)	44 (5.3)	2(0.2)	0 ( 0)	118(14.1)	168	72%
e-mail from a friend	290 (34.8)	103 (12.4)	12(1.4)	2 0.2)	407(48.8)	~1680	24%
Facebook from a friend	59 (7.1)	73 (8.8)	2 (0.2)	0 (0)	134 (16.1)	unknown	unknown
Facebook from study co-ordinator	21 (2.5)	2 (0.2)	0 (0)	0 (0)	23 (2.8)	unknown	unknown
Word of mouth and other	112 (13.4)	37 (4.4)	3 (0.4)	0 (0)	152 (18.2)	unknown	unknown
Total	554 (66.4)	259 (31.0)	19 (2.3)	2 (0.2)	834 (100)	-	-
Self-identified sexuality of the Australian male population (~ %)	97%	2%	<1%	<1%	100%	-	-

Brackets= Percentage of the total number of responders.

These results would suggest that while social media is an innovative method of study recruitment and that an e-mail message from the study coordinator will yield the highest calculable recruitment rate, it is actually an email from a friend inviting study participation most likely to yield the highest number of respondents. Such a method may work particularly well with those populations which are hidden or difficult to access.

## **Chapter 8b: Second phase questionnaire based study**

### **Introduction**

The literature review presented in the earlier chapters revealed anxiety, depression, erectile dysfunction and incontinence as major issues following a prostate cancer treatment.

In the final part of the investigation into prostate cancer survivorship and sexual orientation, this questionnaire study was conducted with the aim of examining more closely the thesis statement as above.

### **Materials and methods for data collection**

#### **Instruments**

##### **Body image**

The Multidimensional Body-Self Relations Questionnaire (MBSRQ) is a self-reporting inventory for the assessment of self-attitudinal aspects of body image. The perceptions and attitudes one holds in relation to one's own physical appearance gives an indication of one's own body image (p. 455)(5). The questionnaire used in this second phase study is a multidimensional assessment and does not yield a total combined score. It is a validated and reliable instrument (6). While the MBSRQ yields seven subscales (appearance evaluation, appearance orientation, fitness evaluation, fitness orientation, health evaluation, health orientation, and illness orientation), the four subscales of appearance orientation, fitness evaluation, fitness orientation and illness orientation were not relevant to the study cohort, and were omitted.

The three remaining subscales (appearance evaluation, health evaluation and health orientation) were considered to be appropriate to administer to a cohort of men regardless of their prostate cancer diagnosis status. As previously described in the methodology chapter (Chapter 5), *appearance evaluation* relates to the feeling of physical attractiveness or satisfaction with one's looks; *health evaluation* is concerned with the feeling of physical health and freedom from physical illness; and *health orientation* relates to the extent of investment in a physically healthy lifestyle.

##### *Scoring the Body Image Scale*

Participants were required to answer all question within Section 5 (Body Image) on a five point Likert Scale (1= Definitely disagree, 2= Mostly disagree, 3=Neither agree nor disagree, 4= Mostly agree, 5= Definitely agree)

Health Evaluation: an example of the scoring system for the MBSRQ subscales.

The constituent survey items for this subscale are questions 52, 60, 71, 56, 64, 68 (Table 5.1) of the Survey Monkey questionnaire. Questions 52, 60, 71 were scored as indicated above (e.g. Definitely disagree = 1, Mostly disagree = 2). However, questions 56, 64 and 68 are contra-indicative items and must be reversed scored (i.e. Definitely disagree = 5, Mostly disagree = 4). The Health Evaluation score is the mean of the constituent items (after reversing contra-indicative items).

**Table 8.1** Scoring system of the MBSRQ subscales

Subscale	Formula to score subscale (Q=Survey Monkey question number)	Corresponding formula within excel spreadsheet (Columns)(x=row)
Appearance Evaluation	$(Q51+Q55+Q59+Q63+Q66-Q67^*-Q69^*+12)/7$	$(DEX+DIx+DMx+DQx+DTx-DUx-DWx+12)/7$
Health Evaluation	$(Q52+Q60+Q71-Q56^*-Q64^*-Q68^*+18)/6$	$(DFx+DNx+DYx-DJx-DRx-DVx+18)/6$
Health Orientation	$(Q53+Q54+Q57+Q58+Q62+Q70-Q61^*-Q65^*+12)/8$	$(DGx+DHx+DKx+DLx+DPx+DXx-DOx-DSx+12)/8$

\*(negative within the formula as this is reverse-scored item)

Table 8.1 shows the method by which the three sub-scales of Body Image (Appearance evaluation, Health evaluation and Health orientation) have been converted from survey monkey responses to the corresponding MSExcel spreadsheet format.

## Self-esteem

Self-esteem, an ability to reflect on one's own emotional evaluation of worth, is both an attitude and a judgement with positive or negative evaluation towards the self (7). Baker and Gringart define self-esteem as 'the overall affective evaluation of one's worth, value or importance' (p. 980)(8). The Rosenberg Self-Esteem Scale was used to assess self-esteem

(Appendix 8.1)(9). This measure has been widely used in social science research and has also been used in previous prostate cancer research (10). The scale shows excellent reliability and validity (11). The Rosenberg Self-Esteem Scale has a cumulative scale from 0 to 30. Scores between 15 and 25 are within normal range. Scores below 15 suggest low self-esteem.

Answers were recorded using a 4-point Likert scale ranging from “Strongly agree” to “Strongly disagree”. Participants responded by indicating a number within the range 1 to 4, which for the questions 41,42,44,46 and 47 were given a corresponding score in the range 3 to 0 (e.g. “Strongly agree”=3, and “Strongly disagree”=0). However, of the ten scale questions, five were reverse scored (questions 43,45,48,49,50). Correspondingly, for these later questions, an answer of “Strongly agree” = 0 and “Strongly disagree” = 3.

The possible cumulative scale ranged from 0-30. Scores between 15 and 25 were within normal range. Scores below 15 suggested low self-esteem.

### **Urinary and sexual function**

The Expanded Prostate Cancer Index Composite (EPIC), is a self-report measure developed to assess the health-related quality of life among men with prostate cancer (12). EPIC, designed to evaluate patient function and bother after prostate cancer treatment, has been validated in men with localised prostate cancer who have undergone surgery, external beam radiation or brachytherapy, with or without the use of hormone (androgen deprivation) therapy (ADT) (12, 13). Although the complete EPIC instrument broadly measures urinary, bowel, sexual and hormonal symptoms, the current study focused on urinary and sexual function domains. Each item response value for the measure of the sexual and urinary functions was converted to a standardised value as per Wei et al (12). For both sexual and urinary functions, the score range was 0–100. Higher scores indicate better function.

### **Procedures**

Ethical approval for the study was granted by the La Trobe University Human Ethics Committee (Approval number 13-006). Recruitment occurred over a three-month period from 1 July 2013 to 30 September 2013. Recruitment for the study commenced with an email

circulated to a convenience sample with instructions to forward the email on to as many men as possible, by posting a message about the study on Facebook, and by encouraging participation by word of mouth. The coordinator asked those contacted to invite friends and other potential respondents to complete the questionnaire (14). The Prostate Cancer Foundation of Australia (PCFA) assisted with recruitment by sending an e-mail to the coordinators of all prostate cancer support groups under the auspices of PCFA, encouraging engagement with this study.

The questionnaire (Appendix 5.1) was administered using an online survey platform with respondents following a link from the email or Facebook page. Responses were anonymous and no identifying information was collected. An overall response rate could not be calculated because the total number of individuals who received information about the study is unknown.

### **Data handling**

For each of the sexual and urinary functions an item response value was converted to a standardised value as outlined by Wei et al (20).

In the Survey Monkey format <https://www.surveymonkey.com/s/MensHealthSurvey1> questions 25 to 33 corresponded to the domain of sexual function, while questions 34 to 40 were concerned with the domain of urinary function (19). In order to score the sexual and urinary functions, the questions listed on survey monkey were initially matched with those on the EPIC scale as described by Wei (Appendix 5.5 and 5.7 respectively) (20).

Standardisation of sexual and urinary functions values were completed (appendix 5.6 and 5.8 respectively) using the excel spreadsheet codes as indicated.

The standardized value for each of the urinary function and sexual function questions were tabulated in the excel spreadsheet.

A final sexual function score was obtained adding the standardized scores of all questions in the domain (Survey Monkey questions 25 to 33) and obtaining an average standardised value.  $(\sum (BV3 \text{ to } CH3))/13$  (Where BV3 and CH3 refer to cell locations on the Excel spreadsheet).



A final urinary function score was obtained adding the standardized scores of all questions in the domain (Survey Monkey questions 34 to 40) and obtaining an average standardised value.  $(\sum (CI3 \text{ to } CT3))/12$  (Where CI3 and CT3 refer to cell locations on the Excel spreadsheet).

For each of the domains (sexual and urinary) the average of the standardized value was calculated and entered onto the original Excel spreadsheet for each participant.

Following the protocol of Wei, the number of non-missing items required to compute a score was 11 for sexual function and 10 for urinary function. If more items were missing than permitted, the score was set to “missing” (20).

At study recruitment closure, results were downloaded from Survey Monkey into an Excel spreadsheet format. Using the scoring systems as outlined, resulting values for each of sexual function, urinary function, self-esteem and body image were calculated for each participant who had provided sufficient data. Body image was represented by three individual scores for Appearance Evaluation, Health Evaluation and Health Orientation rather than by one overall score. These results were added to the excel spreadsheet which was then exported into STATA and SPSS packages for analysis.

## **Study population**

Participants were all men aged 30 years and above and living in Australia. Men who had received a diagnosis of prostate cancer were recruited via e-mail from a friend, e-mail from the study co-ordinator, Facebook request from a friend, and Facebook request from the study co-ordinator. Recruitment for the study was commenced with the study co-ordinator e-mailing his list of contacts. The e-mail requests included females who were then invited to forward the request to eligible males.

A control group of men who had not received a diagnosis of prostate cancer were also recruited similarly.

## **Results**

Of the 877 men who attempted the online questionnaire, six were excluded as they were under 30 years of age and 37 were excluded as they failed to answer any questions, leaving a total of 834 respondents.

Table 8.2 shows the classification of the remaining 834 respondents, according to recruitment method and self-identified sexual orientation.

**TABLE 8.2: SAMPLE SIZE OBTAINED FROM EACH RECRUITMENT METHOD**

Recruitment method	Sexual orientation				Total n(%)
	<i>Straight</i> n(%)	<i>Gay</i> n(%)	<i>Bisexual</i> n(%)	<i>Transgender</i> / other n(%)	
e-mail from a friend	290 (34.8)	103 (12.4)	12 (1.4)	2 (0.2)	407 (48.8)
e-mail from study co-ordinator	72 (8.6)	44 (5.3)	2 (0.2)	0 (0)	118 (14.1)
Facebook from a friend	59 (7.1)	73 (8.8)	2 (0.2)	0 (0)	134 (16.1)
Facebook from study co-ordinator	21 (2.5)	2 (0.2)	0 (0)	0 (0)	23 (2.8)
Word of mouth and other	112 (13.4)	37 (4.4)	3 (0.4)	0 (0)	152 (18.2)
<b>Total</b>	<b>554 (66.4)</b>	<b>259 (31.0)</b>	<b>19 (2.3)</b>	<b>2 (0.2)</b>	<b>834</b>

*%= percentage of total 834*

Table 8.3 shows the classification of the remaining 834 respondents, according to self-identified sexual orientation and previous diagnosis of prostate cancer.

**Table 8.3: Respondents by sexual orientation and prostate cancer diagnosis status**

Sexual orientation (self-identified)	Previous diagnosis of prostate cancer?		Total n(%)
	Yes n (%)	No n (%)	
Straight (Heterosexual)	227 (27.2)	327 (39.2)	554 (66.4)
Gay (Homosexual)	28 (3.4)	231 (27.7)	259 (31.1)
Bisexual	6 (0.7)	13 (1.6)	19 (2.3)
Transgender	0 (0)	0 (0)	0 (0)
Other	0 (0)	2 (0.2)	2 (0.2)
<b>Total</b>	<b>261 (31.3)</b>	<b>573 (68.7)</b>	<b>834</b>

*% = percentage of total 834*

As gay and straight men are the focus of the study, a further 21 respondents (19 bisexual and two who self-identified sexual orientation as 'Other') were excluded from further analysis.

Table 8.4 shows the categorisation of the remaining 813, according to self-identified sexual orientation and previous diagnosis of prostate cancer. It also introduces the code for each group that will be used throughout this chapter:

- Group A = gay men with a prostate cancer diagnosis
- Group B = gay men with no prostate cancer diagnosis
- Group C = straight men with a prostate cancer diagnosis
- Group D = straight men with no prostate cancer diagnosis
- Group E = all men with a prostate cancer diagnosis
- Group F = all men with no prostate cancer diagnosis
- Group G = gay men regardless of prostate cancer diagnosis status
- Group H = straight men regardless of prostate cancer diagnosis status
- Group I = all men regardless of prostate cancer diagnosis status.

**Table 8.4: Classification by prostate cancer diagnosis and sexual orientation**

Sexual orientation (self-identified)	Prostate cancer diagnosis?		Total
	Yes	No	
Gay	<b>Group A</b> 28	<b>Group B</b> 231	Group G 259
Straight	<b>Group C</b> 227	<b>Group D</b> 327	Group H 554
<b>Total</b>	<b>Group E</b> 255	<b>Group F</b> 558	<b>Group I</b> 813

The study further examined respondents according to their choice of treatment intervention; firstly looking at active surveillance, compared to all other treatment methods (Table 8.5) and then at surgery, compared to all other treatment methods (Table 8.6).

**Table 8.5: Classification of groups A and C by treatment intervention or active surveillance**

	Prostate cancer diagnosis		Total
	Treatment intervention S,H,R,B,U,C,O	Active surveillance	
Gay	<b>A1</b> 19	<b>A2</b> 9	<b>A</b> 28
Straight	<b>C1</b> 195	<b>C2</b> 32	<b>C</b> 227
<b>Total</b>	<b>E1</b> 214	<b>E2</b> 41	<b>E</b> 255

*S = surgery, H = hormone therapy, R = radiotherapy, B = brachytherapy, U = high-intensity focused ultrasound, C = cryotherapy, O = other treatment type, AS=active surveillance*

**Table 8.6: Classification of groups A and C by treatment intervention or surgery**

	Prostate cancer diagnosis		Total
	Treatment intervention AS,H,R,B,U,C,O	Surgery	
Gay	<b>A3</b> 9	<b>A4</b> 19	<b>A</b> 28
Straight	<b>C3</b> 84	<b>C4</b> 143	<b>C</b> 227
<b>Total</b>	<b>E3</b> 93	<b>E4</b> 162	<b>E</b> 255

*S = surgery, H = hormone therapy, R = radiotherapy, B = brachytherapy, U = high-intensity focused ultrasound, C = cryotherapy, O = other treatment type, AS=active surveillance*

## **Demographic characteristics**

Table 8.6 –below- which shows demographic outcomes based on sexual orientation indicates that:

- the four groups (A, B, C and D) were ethnically similar, with most (94.2%) men identifying as Caucasian;
- partnership status was directed by sexual orientation rather than by prostate cancer diagnosis: 75.8% of all the straight men were married and 54.4% of all the gay men lived with a male partner;
- the education level of the entire study population was high, with 27.8% having a university degree and a further 29.6% having a postgraduate qualification;
- there was income disparity: those with no diagnosis of prostate cancer accounted for a higher percentage of the upper income bracket group (30.3% gay men, 44.6% straight men with an income greater than \$125,000). This is compared with the average annual total earnings for Australian males which is approximately \$70,000 (15).

**Table 8.7: Frequency values of demographic outcome variables based on sexual orientation**

Variables	Gay men		Straight men		Combined men (gay and straight)		All men by sexual orientation		
	<b>A:</b> Prostate cancer diagnosis n=28 (%)	<b>B :</b> No prostate cancer diagnosis n=231 (%)	<b>C:</b> Prostate cancer diagnosis n=227 (%)	<b>D:</b> No prostate cancer diagnosis n=327 (%)	<b>E</b> Prostate cancer diagnosis n= 255 (%)	<b>F:</b> No prostate cancer diagnosis n=558 (%)	<b>G:</b> All gay men n=259 (%)	<b>H:</b> All straight men n= 554 (%)	<b>I:</b> All men n=813 (%)
<b>Ethnicity</b>									
Caucasian	27 (96.4)	215 (93.1)	220 (96.9)	304 (93.0)	247 (96.9)	519 (88.3)	242 (93.4)	524 (94.6)	766 (94.2)
Aboriginal or Torres Strait Islander	0 (0)	2 (0.9)	2(0.9)	3(0.9)	2 ( 0.8)	5 (0.9)	2 (0.8)	5 (0.9)	7 (0.9)
Asian	1(3.6)	6 (2.6)	1(0.4)	4 (1.2)	2 (0.8)	10 (1.8)	7 (2.7)	5 (0.9)	12 (1.5)
African	0 (0)	1 (0.4)	4 (1.8)	2 (0.6)	4 (1.6)	3 (0.5)	1 (0.4)	6 (1.1)	7(0.9)
Other	0 (0)	7 (3.0)	0 (0)	14 (4.3)	0(0)	21 (3.8)	7 (2.7)	14 (2.5)	21 (2.6)
<b>Partnership status</b>									
Never married/single	8 (28.6)	78 (33.8)	2 (0.9)	20 (6.1)	10 (3.9)	98 (17.6)	86 (33.2)	22 (4.0)	108 (13.3)
Married	0 (0)	4 (1.7)	179 (78.9)	241 (73.7)	179 (70.2)	245 (43.9)	4 (1.5)	420 (75.8)	424 (52.2)
Divorced or separated	4 (14.3)	15 (6.5)	19 (8.4)	23 (7.0)	23 (9.0)	38 (6.8)	19 (7.3)	42 (7.6)	61 (7.4)
Widowed	3 (10.7)	6 (2.6)	7 (3.1)	4 (1.2)	10 (3.9)	10 (1.8)	9 (3.5)	11 (2.0)	20 (2.5)
Living with partner (female)	0 (0)	0 (0)	20 (8.8)	39 (11.6)	20 (7.8)	39 (7.0)	0 (0)	59 (10.6)	59 (7.3)
Living with partner (male)	13 (46.4)	128 (55.4)	0 (0)	0 (0)	13 (5.1)	128 (22.9)	141 (54.4)	0 (0)	141 (17.3)

**Table 8.7: Frequency values of demographic outcome variables based on sexual orientation**

Variables	Gay men		Straight men		Combined men (gay and straight)		All men by sexual orientation		
	<b>A:</b> Prostate cancer diagnosis n=28 (%)	<b>B :</b> No prostate cancer diagnosis n=231 (%)	<b>C:</b> Prostate cancer diagnosis n=227 (%)	<b>D:</b> No prostate cancer diagnosis n=327 (%)	<b>E</b> Prostate cancer diagnosis n= 255 (%)	<b>F:</b> No prostate cancer diagnosis n=558 (%)	<b>G:</b> All gay men n=259 (%)	<b>H:</b> All straight men n= 554 (%)	<b>I:</b> All men n=813 (%)
<b>Highest Level of Education</b>									
Primary school	<b>0 (0)</b>	0 (0)	2 (0.9)	1 (0.3)	2 (0.8)	1 (0.2)	0 (0)	3 (0.5)	3 (0.3)
Secondary school	12 (42.9)	27 (11.7)	69 (30.4)	55 (16.8)	81 (31.8)	82 (14.7)	39 (15.1)	124 (22.3)	163 (20.0)
Certificate or Diploma	5 (17.9)	57 (3.0)	74 (32.6)	71 (21.7)	79 (31.0)	128 (22.9)	62 (23.9)	145 (26.2)	207 (25.5)
University or college degree	4 (14.3)	80 (34.6)	40 (17.6)	102 (31.2)	44 (17.3)	182 (32.6)	84 (32.4)	142 (25.6)	226 (27.8)
Post-graduate	7 (25.0)	67 (29.0)	42 (18.5)	98 (30.0)	49 (19.2)	165 (29.6)	74 (28.6)	140 (25.3)	214 (26.3)
<b>Income</b>									
< \$25,000	6 (21.4)	14 (6.0)	24 (10.6)	15 (4.6)	30 (11.8)	29 (5.2)	20 (7.7)	39 (7.0)	59 (7.3)
\$25,001 – \$50,000	7 (25.0)	28 (12.1)	60 (26.4)	35 (10.7)	67 (26.3)	63 (11.2)	35 (13.5)	95 (17.1)	130 (16.0)
\$50,001 –\$75,000	2 (7.1)	41 (17.7)	58 (25.6)	34 (10.4)	60 (23.5)	75 (13.4)	43 (16.6)	92 (16.6)	135 (16.6)
\$75,001 – \$100,000	6 (21.4)	43 (18.6)	32 (14.1)	47 (14.4)	38 (14.9)	90 (16.1)	49 (18.9)	79 (14.3)	128 (15.7)
\$100,001 – \$125,000	3 (10.7)	32 (13.9)	13 (5.7)	44 (13.5)	16 (6.3)	76 (13.6)	35 (13.5)	57 (10.3)	92 (11.3)
> \$125,000	4 (14.3)	70 (30.3)	32 (14.1)	146 (44.6)	36 (14.1)	216 (38.7)	74 (28.6)	178 (32.1)	252 (31.0)
<b>Health standard</b>									
Excellent	11 (39.3)	77 (33.3)	63 (27.8)	118 (36.1)	74 (29.0)	195 (34.9)	88 (34.0)	181 (32.7)	269 (33.1)



**Table 8.7: Frequency values of demographic outcome variables based on sexual orientation**

Variables	Gay men		Straight men		Combined men (gay and straight)		All men by sexual orientation		
	<b>A:</b> Prostate cancer diagnosis n=28 (%)	<b>B :</b> No prostate cancer diagnosis n=231 (%)	<b>C:</b> Prostate cancer diagnosis n=227 (%)	<b>D:</b> No prostate cancer diagnosis n=327 (%)	<b>E</b> Prostate cancer diagnosis n= 255 (%)	<b>F:</b> No prostate cancer diagnosis n=558 (%)	<b>G:</b> All gay men n=259 (%)	<b>H:</b> All straight men n= 554 (%)	<b>I:</b> All men n=813 (%)
Good	14 (50.0)	121 (52.4)	134 (59.0)	175 (53.5)	148 (58.0)	296 (53.0)	135 (52.1)	309 (55.8)	444 (54.6)
Fair	3 (10.7)	5 (2.2)	29 (12.8)	31 (9.5)	32 (12.5)	58 (10.4)	30 (11.6)	60 (10.8)	90 (11.1)
Poor	0 (0)	6 (2.6)	1 (0.4)	3 (0.9)	1 (0.4)	9 (1.6)	6 (2.3)	4 (0.7)	10 (1.2)
Note: All vertical sub-totals do not add to 100% due to missing data. Group classification: A+C= E, B+D=F, E+F=I.									

## Age and Diagnostic Characteristics

The difference in current age between men diagnosed with prostate cancer (gay men = 64.5 years, straight men= 66.4 years) and those without a diagnosis (gay men= 46.8 years, straight men= 49.9 years) was approximately 17 years. A paired-samples t-test found no significant difference in age at prostate cancer diagnosis between gay men ( $M=60.3$ ,  $sd=5.86$ ,  $CI\ 58.01-62.65$ ) and straight men ( $M=60.7$ ,  $sd=7.28$ ,  $CI\ 59.7-61.7$ ) men,  $t(244)=-0.25$ ,  $p=0.80$ . The age of participants at diagnosis of prostate cancer (Gay=60.3yrs, Straight=60.7yrs) is approximately seven years younger than the 2009 figure of 67.4yrs for the average age of prostate cancer diagnosis of Australian males (16).

The self-reported Gleason score, a more accurate assessment of prostate cancer severity than that of PSA, was shown to be similar for the two groups (gay men= 6.55, straight men= 6.91). A paired-samples t-test found no significant difference in Gleason score at diagnosis between gay men ( $M= 6.55$ ,  $sd= 1.31$ ) and straight men ( $M= 6.91$ ,  $sd=1.30$ ),  $t(193)= -1.17$ ,  $p=0.24$

A paired-samples t-test found no significant difference in PSA at diagnosis between gay men ( $M=6.79$ ,  $sd=2.79$ ,  $CI\ 5.56-8.02$ ) and straight men ( $M=13.24$ ,  $sd=26.9$ ,  $CI\ 9.60-16.92$ ),  $t(228)=0.26$ ,  $p=0.26$

Targeted recruitment resulted in 31.4% of the study population self-identifying as gay, whereas the number of gay men in the general Australian population is considered to be in the range 1.6% to 2.5% (17, 18). While the number of gay men diagnosed with prostate cancer ( $n=28$ ) in the study population is low compared with the corresponding straight group ( $n=227$ ), this figure equates to 11% of the total study population diagnosed with prostate cancer.

There was little difference in the general health standard across the study groups, with about 33% of all respondents considering themselves to have an excellent health standard and about 55% a good health standard. While the current age of the gay and straight men with a diagnosis of prostate cancer (64.5 and 66.4 years respectively) were similar, the ages of the gay and straight men without a diagnosis of prostate cancer were much younger (46.8 and 49.9 years respectively).

For respondents with a prostate cancer diagnosis, the chi squared test for difference in mean indicated no significant difference in terms of demographic variables (age, ethnicity,

education and income) between the gay men (Group A) and the straight men (Group C). That is, the demographic variables (age, ethnicity, education and income) for those with a diagnosis of prostate cancer were shown to be independent of sexual orientation.

### **Correlation analysis**

Tables 8.8 to 8.12 show the correlation coefficients of age and the six outcome variables for all men and stratified according to sexual orientation and prostate cancer diagnosis. The outcome variables were: appearance evaluation, health evaluation, health orientation, self esteem, urinary function and sexual function.

#### *All four groups of participants combined*

Firstly, correlation analyses were performed on the entire sample. The results are presented below in Table 8.8.

#### ***Age***

Table 8.8 shows the correlation coefficients in men (i.e. gay and straight combined) regardless of prostate cancer diagnosis. A significant negative correlation was found between age and urinary function ( $r = -0.322$ ,  $p < 0.01$ ) as well as sexual function score ( $r = -0.541$ ,  $p < 0.01$ ). In addition, a significant positive association was found between age and health orientation ( $r = 0.183$ ,  $p < 0.01$ ) as well as self-esteem score ( $r = 0.181$ ,  $p < 0.01$ ).

#### ***Urinary function***

A significant positive correlation was found between urinary function score and sexual function ( $r = 0.346$ ,  $p < 0.01$ ), appearance evaluation ( $r = 0.155$ ,  $p < 0.01$ ), health evaluation ( $r = 0.266$ ,  $p < 0.01$ ), and self-esteem score ( $r = 0.109$ ,  $p < 0.01$ ).

#### ***Sexual function***

A significant positive association was found between sexual function score and appearance evaluation ( $r = 0.193$ ,  $p < 0.01$ ), health evaluation ( $r = 0.241$ ,  $p < 0.01$ ) and self-esteem score ( $r = 0.121$ ,  $p < 0.01$ ).

#### ***Appearance evaluation***

A significant positive association was found between appearance evaluation score and health evaluation ( $r=0.549$ ,  $p<0.01$ ), health orientation ( $r=0.540$ ,  $p<0.01$ ) and self-esteem score ( $r=0.432$ ,  $p<0.01$ ).

### ***Health evaluation***

A significant positive association was found between health evaluation score and health orientation score ( $r=0.480$ ,  $p<0.01$ ) as well as self-esteem score ( $r=0.451$ ,  $p<0.01$ ).

### ***Health orientation***

A significant positive association was found between health orientation score and self esteem score ( $r=0.381$ ,  $p<0.001$ )

## **GAY MEN WITH A PROSTATE CANCER DIAGNOSIS**

Correlation analyses were performed for the group of gay men with a diagnosis of prostate cancer. The results are presented below in table 8.9 below, and show the correlation coefficients between age and outcome measures for gay men with a prostate cancer diagnosis. A significant positive correlation was found between self-esteem score and sexual function score ( $r=0.561$ ,  $p<0.05$ ) as well as between self-esteem and health evaluation score ( $r=0.753$ ,  $p<0.001$ ).

**Table 8.8: Spearman correlation coefficients for age and outcome measures in all men regardless of prostate cancer diagnosis status**

		Age	Urinary function	Sexual function	Appearance evaluation	Health evaluation	Health orientation	Self-esteem
	Correlation coefficient	1.000			.			
	Sig. (2-tailed)	.			.			
	N	813						
Urinary function	Correlation coefficient	-.322**	1.000					
	Sig. (2-tailed)	<0.01	.					
	N	675	675					
Sexual function	Correlation coefficient	-.541**	.346**	1.000				
	Sig. (2-tailed)	<0.01	<0.01	.				
	N	596	548	596				
Appearance evaluation	Correlation coefficient	.01	.155**	.193**	1.000			
	Sig. (2-tailed)	(0.78)	<.01	<.01			.	
	N	813	675	596	813			
Health evaluation	Correlation coefficient	-.058	.266**	.241**	.549**	1.000	.	
	Sig. (2-tailed)	.10	<.01	<.01	<.01	.		.
	N	813	675	596	813	813		
Health orientation	Correlation coefficient	.183**	.060	.059	.540**	.480**	1.000	
	Sig. (2-tailed)	.000	.119	.147	.000	.000	.	
	N	813	675	596	813	813	813	
Self-esteem	Correlation coefficient	.181**	.109**	.121**	.432**	.451**	.381**	1.000
	Sig. (2-tailed)	<.01	<.01	<.01	<.01	<.01	<.01	.
	N	724	638	561	724	724	724	724

Table 8.9: Spearman correlation coefficients for age and outcome measures in gay men with a prostate cancer diagnosis

		Age	Urinary function	Sexual function	Appearance evaluation	Health evaluation	Health orientation	Self-esteem
Age	Correlation coefficient	<b>1.00</b>						
	Sig. (2-tailed)	.						
	N	28						
Urinary function	Correlation coefficient	.268	<b>1.00</b>					
	Sig. (2-tailed)	.194	.					
	N	25	25					
Sexual function	Correlation coefficient	-.192	-.122	<b>1.00</b>				
	Sig. (2-tailed)	.530	.692	.				
	N	13	13	13				
Appearance evaluation	Correlation coefficient	.316	.371	-.184	<b>1.00</b>			
	Sig. (2-tailed)	.102	.068	.548	.			
	N	28	25	13	28			
Health evaluation	Correlation coefficient	.043	.151	.440	.460*	<b>1.00</b>		
	Sig. (2-tailed)	.827	.472	.133	.014	.		
	N	28	25	13	28	28		
Health orientation	Correlation coefficient	.286	.168	.081	.461*	.350	<b>1.00</b>	
	Sig. (2-tailed)	.139	.423	.793	.013	.067	.	
	N	28	25	13	28	28		
Self esteem	Correlation coefficient	(-.08)	.063	.561*	.241	.753**		<b>1.00</b>
	Sig. (2-tailed)	.707	.766	.046	.227	.000		
	N	27	25	13	27	27		

Note: \*p< 0.05 level (2-tailed) \*\*p<0.01 (2-tailed)

### *Gay men with no prostate cancer diagnosis*

Correlation analyses were performed for the group of gay men without a diagnosis of prostate cancer. The results are presented below in Table 8.10.

#### **Age**

A significant negative association was found between age and urinary function ( $r = -0.175$ ,  $p < 0.05$ ), sexual function score ( $r = -0.307$ ,  $p < 0.001$ ). In addition, significant positive correlation was found between health orientation ( $r = 0.171$ ,  $p < 0.01$ ) and self-esteem score ( $r = 0.230$ ,  $p = 0.001$ ).

#### **Urinary function**

A significant positive correlation was found between urinary function score and sexual function ( $r = 0.277$ ,  $p < 0.001$ ), appearance evaluation ( $r = 0.218$ ,  $p < 0.01$ ), health evaluation ( $r = 0.309$ ,  $p < 0.01$ ) and self-esteem score ( $r = 0.167$ ,  $p < 0.05$ ).

#### **Sexual function**

A significant positive correlation was found between sexual function score and appearance evaluation ( $r = 0.294$ ,  $p < 0.001$ ), health evaluation ( $r = 0.217$ ,  $p < 0.01$ ), health orientation ( $r = 0.153$ ,  $p < 0.05$ ) and self-esteem score ( $r = 0.327$ ,  $p < 0.01$ ).

#### **Appearance evaluation**

A significant positive association was found between appearance evaluation score and health evaluation ( $r = 0.583$ ,  $p < 0.01$ ), health orientation ( $r = 0.621$ ,  $p < 0.01$ ) and self-esteem score ( $r = 0.570$ ,  $p < 0.01$ ).

#### **Health evaluation**

A significant positive association was found between health evaluation score and health orientation ( $r = 0.527$ ,  $p < 0.01$ ) as well as self-esteem score ( $r = 0.373$ ,  $p < 0.01$ ).

#### **Health orientation**

A significant positive association was found between health orientation score and self-esteem score ( $r = 0.361$ ,  $p < 0.01$ ).

**Table 8.10: Spearman correlation for coefficients for age and outcome measures in gay men with no prostate cancer diagnosis**

Variable	Test	Age	Urinary function	Sexual function	Appearance evaluation	Health evaluation	Health orientation	Self-esteem
Age	Correlation coefficient	<b>1.00</b>						
	Sig. (2-tailed)	.						
	N	231						
Urinary function	Correlation coefficient	-.175*	<b>1.00</b>					
	Sig. (2-tailed)	.014	.	.000				
	N	197	197	182				
Sexual function	Correlation coefficient	-.307**	.277**	<b>1.00</b>				
	Sig. (2-tailed)	.000	.000	.				
	N	194	182	194				
Appearance evaluation	Correlation coefficient	.025	.218**	.294**	<b>1.00</b>			
	Sig. (2-tailed)	.710	.002	.000	.			
	N	231	197	194	231			
Health evaluation	Correlation coefficient	-.075	.309**	.217**	.583**	<b>1.00</b>		
	Sig. (2-tailed)	.255	.000	.002	.000	.		
	N	231	197	194	231	231		
Health orientation	Correlation coefficient	.171**	.127	.153*	.621**	.527**	<b>1.00</b>	
	Sig. (2-tailed)	.009	.076	.033	.000	.000	.	
	N	231	197	194	231	231	231	
Self-esteem	Correlation coefficient	.230**	.167*	.327**	.570**	.373**	.361**	<b>1.00</b>
	Sig. (2-tailed)	.001	.023	.000	.000	.000	.000	.
	N	206	186	183	206	206	206	206

Note: \*p< 0.05 level (2-tailed) \*\*p<0.01 (2-tailed)



### *Straight men with a prostate cancer diagnosis*

Correlation analyses were performed for the group of straight men with a diagnosis of prostate cancer. The results are presented below in table 8.11

#### **Age**

No significant correlations were found between age and the outcome measures ( $p>0.01$ )

#### **Urinary function**

A significant positive correlation was found between urinary function score and health evaluation score ( $r=0.218$ ,  $p<0.01$ ).

#### **Sexual function**

No significant correlations were found between sexual function scores and age as well as with other outcome measures ( $p>0.01$ ).

#### **Appearance evaluation**

A significant positive correlation was found between appearance evaluation score and health evaluation ( $r=0.508$ ,  $p<0.01$ ), health orientation ( $r=0.471$ ,  $p<0.01$ ) and self-esteem score ( $r=0.258$ ,  $p<0.01$ ).

#### **Health evaluation**

A significant positive correlation was found between health evaluation score and health orientation score ( $r=0.482$ ,  $p<0.01$ ) as well as self-esteem score ( $r=0.510$ ,  $p<0.01$ ).

#### **Health orientation**

A significant positive correlation was found between health orientation score and self-esteem score ( $r=0.346$ ,  $p<0.01$ ).

**Table 8.11: Spearman correlation coefficients for age and outcome measures in straight men with a prostate cancer diagnosis**

Variable	Test	Age	Urinary function	Sexual function	Appearance evaluation	Health evaluation	Health orientation	Self-esteem
Age	Correlation coefficient	<b>1.00</b>						
	Sig. (2-tailed)	.						
	N	227						
Urinary function	Correlation coefficient	.033	<b>1.00</b>					
	Sig. (2-tailed)	.666	.					
	N	171	171					
Sexual function	Correlation coefficient	-.237*	.151	<b>1.00</b>				
	Sig. (2-tailed)	.011	.143	.				
	N	115	95	115				
Appearance evaluation	Correlation coefficient	.065	.125	.187*	<b>1.00</b>			
	Sig. (2-tailed)	.327	.104	.046	.			
	N	227	171	115	227			
Health evaluation	Correlation coefficient	.118	.218**	.183	.508**	<b>1.00</b>		
	Sig. (2-tailed)	.077	.004	.050	.000	.		
	N	227	171	115	227	227		
Health orientation	Correlation coefficient	.065	.096	.180	.471**	.482**	<b>1.00</b>	
	Sig. (2-tailed)	.331	.212	.054	.000	.000	.	
	N	227	171	115	227	227	227	
Self-esteem	Correlation coefficient	.110	.177*	.214*	.258**	.510**	.346**	<b>1.00</b>
	Sig. (2-tailed)	.124	.025	.027	.000	.000	.000	.
	N	198	159	107	198	198	198	198

Note: \*p< 0.05 level (2-tailed) \*\*p<0.01 (2-tailed)

#### *STRAIGHT MEN WITHOUT PROSTATE CANCER DIAGNOSIS*

Correlation analyses were performed for the group of straight men without a diagnosis of prostate cancer. The results are presented in table 8.12 below.

##### ***Age***

A significant negative correlation was found between age and urinary function score ( $r=-0.324$ ,  $p<0.001$ ) as well as sexual function score ( $r=-0.408$ ,  $p<0.01$ ).

##### ***Urinary function***

A significant positive correlation was found between urinary function score and sexual function score ( $r=0.225$ ,  $p<0.001$ ) as well as health evaluation score ( $r=0.216$ ,  $p<0.01$ ).

##### ***Sexual function***

A significant positive correlation was found between sexual function score and appearance evaluation ( $r=0.211$ ,  $p<0.001$ ), health evaluation ( $r=0.298$ ,  $p<0.01$ ), health orientation ( $r=0.209$ ,  $p=0.01$ ) and self-esteem score ( $r=0.251$ ,  $p<0.01$ ).

##### ***Appearance evaluation***

A significant positive correlation was found between appearance evaluation and health evaluation ( $r=0.545$ ,  $p<0.01$ ), health orientation ( $r=0.542$ ,  $p<0.01$ ) and self-esteem score ( $r=0.445$ ,  $p<0.01$ ).

##### ***Health evaluation***

A significant positive correlation was found between health evaluation score and health orientation score ( $r=0.516$ ,  $p<0.001$ ) as well as self-esteem score ( $r=0.463$ ,  $p<0.001$ ).

##### ***Health orientation***

A significant positive correlation was found between health orientation score and self-esteem score ( $r=0.436$ ,  $p<0.01$ ).

Table 8.13 shows the frequency of co-morbid conditions for each group of respondents. The table indicates that co-morbidity across groups were medically similar, except for the high percentage of depression/anxiety in the group of gay men with no diagnosis of prostate cancer.

**Table 8.12: Spearman correlation coefficients for age and outcome measures in straight men without prostate cancer diagnosis**

Variable	Test	Age	Urinary function	Sexual function	Appearance evaluation	Health evaluation	Health orientation	Self-esteem
Age	Correlation coefficient	<b>1.00</b>						
	Sig. (2-tailed)	.						
	N	327						
Urinary function	Correlation coefficient	-.324**	<b>1.00</b>					
	Sig. (2-tailed)	.000	.					
	N	282	282					
Sexual function	Correlation coefficient	-.408**	.225**	<b>1.00</b>				
	Sig. (2-tailed)	.000	.000	.				
	N	274	258	274				
Appearance evaluation	Correlation coefficient	-.021	.095	.211**	<b>1.00</b>			
	Sig. (2-tailed)	.704	.113	.000	.			
	N	327	282	274	327			
Health evaluation	Correlation coefficient	-.054	.216**	.298**	.545**	<b>1.00</b>		
	Sig. (2-tailed)	.335	.000	.000	.000	.		
	N	327	282	274	327	327		
Health orientation	Correlation coefficient	.093	.081	.209**	.542**	.516**	<b>1.00</b>	
	Sig. (2-tailed)	.093	.175	.001	.000	.000	.	
	N	327	282	274	327	327	327	
Self-esteem	Correlation coefficient	.068	.099	.251**	.445**	.463**	.436**	<b>1.00</b>
	Sig. (2-tailed)	.248	.104	.000	.000	.000	.000	.
	N	293	268	258	293	293	293	293
Note: ** $p < 0.01$ (2-tailed)								

**Table 8.13: Co-morbidity by prostate cancer diagnosis status and sexual orientation**

Variable	Gay men		Straight men		Combined men (gay and straight)		All men n=813
	<i>Prostate cancer diagnosis n=28</i>	<i>No prostate cancer diagnosis n=231</i>	<i>Prostate cancer diagnosis n=227</i>	<i>No prostate cancer diagnosis n=327</i>	<i>Prostate cancer diagnosis n= 255</i>	<i>No prostate cancer diagnosis n= 558</i>	
	<i>A</i>	<i>B</i>	<i>C</i>	<i>D</i>	<i>E</i>	<i>F</i>	<i>I</i>
<b>Medical condition as a percentage of the total number listed</b>							
Arthritis, rheumatism	21.7	7.7	20.0	14.4	20.2	11.2	14.8
Diabetes	3.3	4.8	7.5	7.6	7.0	6.3	6.6
Inflammatory bowel disease	5.0	3.1	3.1	1.3	3.3	2.1	2.6
Stomach ulcer	1.7	1.7	0.9	0.8	1.0	1.2	1.1
Asthma, chronic lung disease, bronchitis or emphysema	11.7	14.8	8.7	14.7	9.1	14.7	12.5
Heart failure	0	0.9	2.1	0.8	1.9	0.8	1.2
AIDS-defining illness	1.7	3.1	0	0	0.2	1.5	1.0
Kidney disease	1.7	0.9	1.9	2.0	1.9	1.5	1.6
Stroke	0	1.7	2.6	2.0	2.3	1.9	2.0
High blood pressure	21.7	20.5	23.2	23.3	23.0	22.0	22.3
Heart attack or myocardial infarction	3.3	1.7	3.1	3.5	3.1	2.7	2.8
Angina	3.3	3.7	6.1	5.8	5.8	4.8	5.2
Liver disease or cirrhosis	0	2.3	1.2	1.0	1.0	1.6	1.4
Depression/anxiety	16.7	27.8	14.3	17.7	14.6	22.5	19.3
Cancer (other than prostate cancer or non-melanoma skin cancer)	8.3	5.4	5.4	5.1	5.8	5.2	5.4
Total number of conditions listed	60	352	426	395	486	747	1233
Note: *p< 0.05 level (2-tailed) **p<0.01 (2-tailed)							

*Note: Each medical condition is indicated as a percentage of the total number of conditions listed for a particular group*

Table 8.14 shows that, regardless of sexual orientation, a high percentage of men had undergone surgery as their primary treatment for prostate cancer (gay=67.8%, straight=63%, gay and straight=63.5%) compared with active surveillance as primary treatment (gay=32.1%, straight=14.1%, gay and straight=16.1%).

**TABLE 8.14: PRIMARY TREATMENT AND DIAGNOSTIC CHARACTERISTICS ACROSS GROUPS**

Variable	<i>Prostate cancer diagnosis (Gay)</i> <i>n=28 (%)</i>	<i>Prostate cancer diagnosis (Straight)</i> <i>n=227 (%)</i>	<i>Prostate cancer diagnosis (Gay and Straight combined)</i> <i>n= 255(%)</i>
	<b>A</b>	<b>C</b>	<b>E</b>
<b>Primary treatment n (% of n in the category)</b>			
Surgery	19 (67.86)	143 (63.00)	162 (63.53)
Active surveillance	9 (32.14)	32 (14.10)	41 (16.08)
Hormone therapy	0 (0)	40 (17.62)	40 (15.69)
Radiotherapy	0 (0)	25 (11.01)	25 (9.80)
Brachytherapy	1 (3.57)	14 (6.16)	15 (5.88)
HIFU*, cryotherapy, other	1 (3.57)	7 (3.08)	8 (3.14)
Number of treatments per category	30	261	291
<p><i>*HIFU = high-intensity focused ultrasound</i></p> <p>Total (% of n in the category) per column may be &gt; 100% as some men had more than one type of primary therapy</p>			

### **Results: by outcome measures**

The violations of normality identified by the Shapiro-Wilk test and the between group design of the study were the basis for employing a Kruskal-Wallis ANOVA for each of the outcome variables. The critical value was adjusted to 0.01 to account for multiple comparisons.

Appearance evaluation showed no significant differences across the four groups (gay men with prostate cancer, gay men without prostate cancer, straight men with prostate cancer, straight men without prostate cancer), ( $H(3)=4.34$ ,  $p=0.227$ ). In contrast, significant differences were found for health *evaluation*, *health orientation*, *self-esteem*, *urinary function* and *sexual function* scores across the four groups ( $p<0.01$ ). Post-hoc comparisons using the Mann-Whitney U test were subsequently conducted for these five outcome variables and are detailed in the sections to follow. Table 8.15 shows the mean values of the main outcome variables stratified by group.

**Table 8.15: Scores of outcome variables**

	Gay men		Straight men		Combined men (gay and straight)			All men by sexual orientation	
	<i>Prostate cancer diagnosis</i> <i>n=28(sd)</i>	<i>No prostate cancer diagnosis</i> <i>n=231(sd)</i>	<i>Prostate cancer diagnosis</i> <i>n=227(sd)</i>	<i>No prostate cancer diagnosis</i> <i>n=327(sd)</i>	<i>Prostate cancer diagnosis</i> <i>n= 255(sd)</i>	<i>No prostate cancer diagnosis</i> <i>n= 558(sd)</i>	<i>All men</i> <i>n=813(sd)</i>	<i>All gay men</i> <i>n=259(sd)</i>	<i>All straight men</i> <i>n= 554(sd)</i>
	<i>A</i>	<i>B</i>	<i>C</i>	<i>D</i>	<i>E</i>	<i>F</i>	<i>I</i>	<i>G</i>	<i>H</i>
<b>Body image score (sd)</b>	<i>Mean (sd)</i>	<i>Mean (sd)</i>	<i>Mean (sd)</i>	<i>Mean (sd)</i>	<i>Mean (sd)</i>	<i>Mean (sd)</i>	<i>Mean (sd)</i>	<i>Mean (sd)</i>	<i>Mean (sd)</i>
Appearance evaluation(sd)	3.32 (0.69)	3.11 (0.95)	3.19 (0.71)	3.28 (0.81)	3.20 (0.71)	3.21 (0.88)	3.21 (0.83)	3.13 (0.93)	3.24 (0.77)
Health evaluation(sd)	3.60 (0.78)	3.61 (0.72)	3.58 (0.70)	3.80 (0.73)	3.58 (0.71)	3.21 (0.74)	3.67 (0.73)	3.61 (0.73)	3.71 (0.73)
Health orientation(sd)	3.93 (0.70)	3.42 (0.78)	3.66 (0.74)	3.48 (0.79)	3.70(0.74)	3.47 (0.79)	3.54 (0.78)	3.48 (0.79)	3.56 (0.77)
<b>Self esteem score (sd)</b>	23.93 (5.60)	21.09 (5.85)	23.76 (4.93)	23.44 (5.17)	23.82 (4.97)	22.44 (5.64)	22.88 (5.47)	21.42 (5.88)	23.57 (5.07)
<b>Urinary function score (sd)</b>	71.68 (10.07)	77.92 (6.74)	73.26 (8.97)	79.13 (6.74)	72.92 (9.21)	78.56 (6.87)	76.94 (8.04)	77.22 (7.43)	76.91 (8.16)
<b>Sexual function score (sd)</b>	42.33 (14.94)	68.30 (14.16)	37.34 (20.75)	68.94 (15.98)	37.98 (20.43)	68.38 (15.37)	61.92 (20.71)	66.67 (15.52)	59.60 (22.68)
<p><i>Note: Scores: Appearance evaluation [1–5], health evaluation [1–5], health orientation [1–5], self esteem [0–30], urinary function [0–100], sexual function [0–100];</i></p> <p><i>sd = Standard deviation</i></p>									



### *Health evaluation*

A Kruskal-Wallis ANOVA found a statistically significant difference between the four groups on health evaluation,  $H(3)=16.651$ ,  $p<0.01$

No significant differences were observed in *health evaluation* scores of gay and straight men with prostate cancer ( $p=0.92$ )

The *health evaluation* score in gay men without prostate cancer ( $Md=3.833$ ,  $n=231$ ) was significantly lower compare with straight men without prostate cancer ( $Md=4.000$ ,  $n=327$ ),  $U=32183.50$ ,  $p=0.003$  (effect size= 0.13; 2-tailed).

No significant difference in the *health evaluation* score was found between gay men with prostate cancer ( $Md=4.000$ ,  $n=28$ ) and gay men with no prostate cancer ( $Md=3.833$ ,  $n=231$ ),  $U=3196.50$ ,  $p=0.92$  (2-tailed).

### *Health orientation*

A Kruskal-Wallis ANOVA found a statistically significant difference between the four groups on health orientation,  $H(3)=22.154$ ,  $p<0.01$

No significant differences were observed in *health orientation* scores of gay and straight men with prostate cancer ( $p>0.021$ )

The *health orientation* score in gay men with prostate cancer ( $Md=4.125$ ,  $n=28$ ) was significantly greater (improved) compared with gay men without prostate cancer ( $Md=3.625$ ,  $n=231$ ),  $U=1850.00$ ,  $p<0.01$  (effect size=0.226; 2-tailed).

The *health orientation* scores in straight men with a prostate cancer ( $Md=3.875$ ,  $n=227$ ) was significantly greater (improved) compared with straight men without prostate cancer ( $Md=3.625$ ,  $n=327$ ),  $U=31914.00$ ,  $p<0.01$  (effect size=0.12; 2-tailed).

No significant differences were observed in *health orientation* scores between gay men without prostate cancer and straight men without prostate cancer ( $p=0.538$ ).

### *Self esteem*

A Kruskal-Wallis ANOVA found a statistically significant difference between the four groups on self-esteem,  $H(3)=28.789$ ,  $p<0.01$

No significant differences were observed in *self-esteem* scores of gay and straight men with prostate cancer ( $p>0.584$ )

The *self-esteem* score in gay men with no prostate cancer ( $Md=21.000$ ,  $n=206$ ) was significantly lower compared with straight men with no prostate cancer ( $Md=24.000$ ,  $n=293$ )  $U=22942.50$ ,  $p<0.01$  (effect size= 0.205; 2-tailed). (small effect size)

#### *Urinary function*

A Kruskal-Wallis ANOVA found a statistically significant difference between the four groups on urinary function,  $H(3)=72.78$ ,  $p<0.01$

No significant differences were observed in *urinary function* scores of gay and straight men with prostate cancer ( $p=0.513$ )

No significant differences were observed in *urinary function* scores between gay men without prostate cancer and straight men without prostate cancer ( $p=0.039$ ).

The *urinary function* score in gay men with prostate cancer ( $Md=6.742$ ,  $n=25$ ) was significantly lower (impaired) compared with gay men without prostate cancer ( $Md=8.058$ ,  $n=197$ ),  $U=1482.00$ ,  $p<0.01$  (effect size= 0.219; 2-tailed). (small effect size)

The *urinary function* score in straight men with a prostate cancer diagnosis ( $Md=7.575$ ,  $n=171$ ) was significantly lower (impaired) compared with straight men with no prostate cancer diagnosis ( $Md=8.058$ ,  $n=282$ ),  $U=13573.50$ ,  $p<0.01$  (effect size= 0.369; 2-tailed). (large effect size).

#### *Sexual function scores*

A Kruskal-Wallis ANOVA found a statistically significant difference between the four groups on sexual function,  $H(3)=170.227$   $p<0.01$

No significant differences were observed in *sexual function* scores between gay men without prostate cancer and straight men without prostate cancer.

No significant differences were observed in *sexual function* scores of gay and straight men with prostate cancer.

## Results: by sexual orientation

*All gay men with a diagnosis of prostate cancer vs. all straight men with a diagnosis of prostate cancer:*

No significant differences were observed in *appearance evaluation*, *health evaluation*, *health orientation*, *self-esteem*, *urinary function* and *sexual function* scores of gay and straight men with prostate cancer ( $p > 0.021$ ).

*All gay men with a diagnosis of prostate cancer vs. all gay men without a diagnosis of prostate cancer:*

The *health orientation* score in gay men with prostate cancer (Md=4.125, n=28) was significantly greater compared with gay men without prostate cancer (Md=3.625, n=231),  $U = 1850.00$ ,  $p < 0.01$  (effect size=0.226; 2-tailed).

The *urinary function* score in gay men with prostate cancer (Md=6.742, n=25) was significantly lower compared with gay men without prostate cancer (Md=8.058, n=197),  $U = 1482.00$ ,  $p < 0.01$  (effect size= 0.219; 2-tailed).

The *sexual function* score in gay men with a prostate cancer (Md=3.785, n=13) was significantly lower compared with gay men with no prostate cancer (Md=6.923, n=194),  $U = 271.00$ ,  $p < 0.001$  (effect size=0.329; 2-tailed).

Similarly, no significant difference in *self-esteem* scores was observed between gay men with prostate cancer (Md=24.000, n=27) and gay men without prostate cancer (Md=21.000, n=206),  $U = 1971.00$ ,  $p = 0.014$  (2-tailed).

All straight men with a diagnosis of prostate cancer vs. all straight men without a prostate cancer diagnosis:

*All straight men with a diagnosis of prostate cancer vs. all straight men without a prostate cancer diagnosis*

The *health evaluation* score in straight men with prostate cancer (Md=3.833, n=227) was significantly lower compared with straight men with no prostate cancer diagnosis (Md=4.000, n=327),  $U = 30203.00$ ,  $p < 0.01$  (effect size= 0.159; 2-tailed).

*The health orientation* scores in straight men with a prostate cancer (Md=3.875, n=227) was significantly greater compared with straight men without prostate cancer (Md=3.625, n=327),  $U=31914.00$ ,  $p=0.005$  (effect size=0.120; 2-tailed).

*The self-esteem* score in straight men with a prostate cancer diagnosis (Md=26.000, n=198) was significantly greater compared with straight men with no prostate cancer diagnosis (Md=24.000, n=293),  $U=22942.50$ ,  $p<0.01$  (effect size= 0.019; 2-tailed).

*The urinary function* score in straight men with a prostate cancer diagnosis (Md=7.575, n=171) was significantly lower compared with straight men with no prostate cancer diagnosis (Md=8.058, n=282),  $U=13573.50$ ,  $p<0.01$  (effect size= 0.369; 2-tailed).

*The sexual function* scores of straight men with a prostate cancer diagnosis (Md=3.558, n=151) was significantly lower compared with straight men with no prostate cancer diagnosis (Md=7.308, n=274),  $U=3964.50$ ,  $p<0.01$  (effect size= 0.591; 2-tailed).

No significant difference was observed in *appearance evaluation* scores between straight men with a prostate cancer and straight men with no prostate cancer,  $U=34274.50$ ,  $p=0.125$  (2-tailed).

*The health evaluation* score in gay men without prostate cancer (Md=3.833, n= 231) was significantly lower compare with straight men without prostate cancer (Md=4.000, n=327),  $U=32183.50$ ,  $p=0.003$  (effect size= 0.126; 2-tailed).

*The self-esteem* score in gay men with no prostate cancer (Md=21.000, n=206) was significantly lower compared with straight men with no prostate cancer (Md=24.000, n=293)  $U=22942.50$ ,  $p<0.01$  (effect size= 0.205; 2-tailed).

No significant differences were observed in *sexual function*, *health orientation*, and *urinary function* scores between gay men without prostate cancer and straight men without prostate cancer,  $p>0.039$ .

*All gay men with prostate cancer having had surgery as primary treatment vs. all straight men with prostate cancer having had surgery as primary treatment:*

The *health orientation* score in gay men who had undergone surgery to treat prostate cancer (Md=4.125, n=19) was significantly higher compared with straight men who had

undergone surgery to treat prostate cancer (Md=3.813, n=143), U=950.00, p=0.033 (2 tailed).

No significant differences were observed in *urinary function, sexual function, health evaluation, appearance evaluation or self-esteem* scores between the cohort of gay men with prostate cancer who had undertaken surgery compared to the cohort of straight men with prostate cancer who had undertaken surgery.  $p>0.3$

*All gay men with prostate cancer (active surveillance) vs. all straight men with prostate cancer (active surveillance):*

Analysis of the above groups was not undertaken due to low n value.

*All men with a diagnosis of prostate cancer vs. all men without a diagnosis of prostate cancer:*

The *health evaluation* scores between men with prostate cancer (Md=3.833, n=225) and men with no prostate cancer (Md=3.833, n=558) were significantly different, albeit with identical group medians, U=62597.50, p=0.006 (effect size = 0.097; 2-tailed).

The *health orientation* score in men with prostate cancer (Md=3.875, n=225) was significantly higher compared with men without prostate cancer (Md=3.625, n=558), U=58375.50, p<0.001 (effect size=0.144; 2-tailed).

The *self-esteem* score in men with a prostate cancer (Md=26.000, n=225) was significantly higher compared with men without prostate cancer (Md=23.000, n=449), U=48958.00, p=0.006 (effect size=0.103; 2-tailed).

The *urinary function* score in men with prostate cancer (Md=7.575, n= 196) was significantly lower compared with men without prostate cancer (Md=8.058, n=479), U=28061.50, p<0.001 (effect size=0.318; 2-tailed).

The *sexual function* score in men with prostate cancer (Md=3.592, n= 128) is significantly lower compared to the cohort with no prostate cancer (Md=7.308, n=468), U= 7536.50, p<0.001 (effect size=0.532; 2-tailed).

No significant difference was found in *appearance evaluation* scores between men with a prostate cancer (Md=3.429, n=225) and men without prostate cancer (Md=3.429, n=558), U= 69328.00, p=0.558 (2-tailed).

Table 8.17 shows the results of the chi-square test of independence and effect size for sexual orientation, prostate cancer status, partnership status and outcome measures.

**Table 8.17: Chi-square test of independence (with Yates Continuity Correction) for sexual orientation, prostate cancer status, partnership status and outcome measures**

	Appearance evaluation	Health evaluation	Health orientation	Self-esteem	Urinary function	Sexual function
Sexual orientation (1=Gay vs 0=Straight)	$\chi^2$ (1, N=813) =10.822, p<.01*, $\phi$ =-0.119	$\chi^2$ (1, N=813) =1.570, p=0.21, $\phi$ =-0.05	$\chi^2$ (1, N=813) =0.000, p<.01, $\phi$ =-0.002	$\chi^2$ (1, N=813) =2.683, p=0.10, $\phi$ =-0.061	$\chi^2$ (1, N=813)=1.946, p=0.16, $\phi$ =0.052	$\chi^2$ (1, N=813) =29.948, p<0.01*, $\phi$ =0.195
Cancer Dx (1=Cancer; 0=No cancer)	$\chi^2$ (1, N=813) =2.013, p=0.16, $\phi$ =0.053	$\chi^2$ (1, N=813) =0.123, p=0.73, $\phi$ =-0.18	$\chi^2$ (1, N=813) =0.704, p=0.40, $\phi$ =0.034	$\chi^2$ (1, N=813) =0.647, p=0.42, $\phi$ =0.032	$\chi^2$ (1, N=813) =12.276, p<.01*, $\phi$ =-0.126	$\chi^2$ (1, N=813) =253.166, p<0.01*, $\phi$ =-0.561
Has partner (1=has partner; 0=no partner)	$\chi^2$ (1, N=255) =0.848, p=0.36, $\phi$ =0.072	$\chi^2$ (1, N=255) =0.000, p=1.00, $\phi$ =0.013	$\chi^2$ (1, N=255) =1.545, p=0.21, $\phi$ =0.099	$\chi^2$ (1, N=255) =0.651, p=0.42, $\phi$ =0.065	$\chi^2$ (1, N=255) =678, p=0.41, $\phi$ =-0.064	$\chi^2$ (1, N=255) =.569, p=0.45, $\phi$ =0.062
Gay vs Straight (Cancer)	$\chi^2$ (1, N=255) =0.031, p=0.86, $\phi$ =0.028	$\chi^2$ (1, N=255) =3.073, p=0.15, $\phi$ =-0.116	$\chi^2$ (1, N=255) =0.045, p=0.83, $\phi$ =0.039	$\chi^2$ (1, N=255) =0.241, p=0.62, $\phi$ =0.048	$\chi^2$ (1, N=255) =1.261, p=0.26, $\phi$ =0.085	$\chi^2$ (1, N=255) =0.000, p=1.00, $\phi$ =0.002
Gay vs Straight (No cancer)	$\chi^2$ (1, N=558) =11.062, p=.01*, $\phi$ =-.145	$\chi^2$ (1, N=558) =0.629, p=0.43, $\phi$ =-0.042	$\chi^2$ (1, N=558) =0.000, p=1.00, $\phi$ =0.001	$\chi^2$ (1, N=558) =3.386, p=0.07, $\phi$ =-0.083	$\chi^2$ (1, N=558) =0.009, p=0.93, $\phi$ =-0.009	$\chi^2$ (1, N=558) =0.653, p=0.42, $\phi$ =0.038
Cancer vs no cancer (Gay)	$\chi^2$ (1, N=259) =2.029, p=0.15, $\phi$ =0.102	$\chi^2$ (1, N=259) =1.232, p=0.27, $\phi$ =-0.093	$\chi^2$ (1, N=259) =0.246, p=0.62, $\phi$ =0.054	$\chi^2$ (1, N=259) =1.326, p=0.25, $\phi$ =0.087	$\chi^2$ (1, N=259) =0.000, p=1.00, $\phi$ =0.004	$\chi^2$ (1, N=259) =42.273, p<.01*, $\phi$ =-0.418
Cancer vs no cancer (Straight)	$\chi^2$ (1, N=554) =0.017, p=0.90, $\phi$ =-0.010	$\chi^2$ (1, N=554) =0.031, p=0.86, $\phi$ =-0.016	$\chi^2$ (1, N=554) =0.311, p=0.58, $\phi$ =0.031	$\chi^2$ (1, N=554) =0.011, p=0.92, $\phi$ =-0.009	$\chi^2$ (1, N=554) =11.638, p=0.001*, $\phi$ =-0.150	$\chi^2$ (1, N=554) =182.360, p<.01*, $\phi$ =-0.577
Gay vs Straight (Surgery exclusive)	$\chi^2$ (1, N=158) =18.639, p=0.67, $\phi$ =-0.343	$\chi^2$ (1, N=158) =34.62, p=0.016, $\phi$ =0.468	$\chi^2$ (1, N=158) =34.432, p=0.04, $\phi$ =0.467	$\chi^2$ (1, N=146) =19.293, p=0.44, $\phi$ =0.364	$\chi^2$ (1, N=128) =32.530, p=0.54, $\phi$ =0.504	$\chi^2$ (1, N=74) =53.258, p=0.12, $\phi$ =0.848

Table 8.17 shows the Chi squared test of independence for sexual orientation, prostate cancer status, partnership status and treatment by surgery in accord with the six outcome variables. The critical value was adjusted to 0.01 to correct for multiple chi-squared tests. Effect size was determined according to Cohen(19) ( $\phi > 0.5$ = large,  $0.5-0.3$  = moderate,  $0.3-0.1$  = small and  $<0.01$ = trivial).

A significant association between prostate cancer status (cancer vs no cancer) in gay men and sexual function was found with moderate effect size,  $\chi^2(1,259) = 42.273$ ,  $p < 0.001$ ,  $\phi = 0.418$ . In addition, a significant association between prostate cancer status in straight men and sexual function was found with a large effect size,  $\chi^2(1, 554) = 182.360$ ,  $p < 0.01$ ,  $\phi = 0.577$ .

A significant association between prostate cancer status in straight men and urinary function was found with a small effect size,  $\chi^2(1, 554) = 11.638$ ,  $p = 0.01$ ,  $\phi = 0.150$ .

A significant association between sexual orientation (gay vs straight) with no prostate cancer and appearance evaluation was found with a small effect size,  $\chi^2(1,558) = 11.062$ ,  $p < .01$ ,  $\phi = 0.145$ . However age was not found to be a mediating variable (Refer to Table 8.8, appearance evaluation/age cell)

A significant association between sexual orientation (gay vs straight) and appearance evaluation was found with a small effect size,  $\chi^2(1,813) = 10.822$ ,  $p = 0.01$ ,  $\phi = 0.119$

A significant association between sexual orientation (gay vs straight) and sexual function was found with a small effect size,  $\chi^2(1,813) = 29.948$ ,  $p < 0.01$ ,  $\phi = 0.195$

A significant association between prostate cancer status and urinary function was found with a small effect size,  $\chi^2(1,813) = 12.276$ ,  $p < 0.01$ ,  $\phi = 0.126$

A significant association between prostate cancer status and sexual function was found with a large effect size,  $\chi^2(1,813) = 253.166$ ,  $p < 0.01$ ,  $\phi = 0.561$

No association was found between treatment via surgery and sexual orientation in regard to the outcome variables.

Table 8.18 shows a chi squared test of independence (Pearson Chi-Square) that indicated a significant association between sexual function score and education level with a small size effect,  $\chi^2(4,813)=43.242$ ,  $p<0.01$ ,  $\phi=0.231$ , as well as income level with a moderate effect size  $\chi^2(5,796)$ ,  $p<0.01$ ,  $\phi=0.369$ . In addition, a significant association was found between self-esteem and ethnicity with a small effect size,  $\chi^2(4,813)=13.756$ ,  $p<0.01$ ,  $\phi=0.130$

**Table 8.18: Chi-square test of independence (Pearson Chi-Square) for education level, ethnicity and outcome measures**

	Appearance evaluation	Health evaluation	Health orientation	Self-esteem	Urinary function	Sexual function
Education level (all men)	$\chi^2(4, N=813)=1.311$ , $p=0.86$ , $\phi=0.040$	$\chi^2(4, N=813)=10.234$ , $p=0.04^*$ , $\phi=0.112$	$\chi^2(4, N=813)=2.844$ , $p=0.58$ , $\phi=0.059$	$\chi^2(4, N=813)=3.613$ , $p=0.46$ , $\phi=0.067$	$\chi^2(4, N=813)=6.417$ , $p=0.17$ , $\phi=0.089$	$\chi^2(4, N=813)=43.242$ , $p<0.01^*$ , $\phi=0.231$
Income level (all men)	$\chi^2(5, N=796)=2.665$ , $p=0.75$ , $\phi=0.058$	$\chi^2(5, N=796)=3.033$ , $p=0.70$ , $\phi=0.062$	$\chi^2(5, N=796)=5.350$ , $p=0.38$ , $\phi=0.082$	$\chi^2(5, N=796)=10.431$ , $p=0.06$ , $\phi=0.114$	$\chi^2(5, N=796)=13.044$ , $p=0.02^*$ , $\phi=0.128$	$\chi^2(5, N=796)=108.367$ , $p<0.01^*$ , $\phi=0.369$
Ethnicity (all men)	$\chi^2(4, N=813)=2.117$ , $p=0.75$ , $\phi=0.051$	$\chi^2(4, N=813)=2.135$ , $p=0.71$ , $\phi=0.051$	$\chi^2(4, N=813)=12.986$ , $p=0.01^*$ , $\phi=0.126$	$\chi^2(4, N=813)=13.756$ , $p=0.01^*$ , $\phi=0.130$	$\chi^2(4, N=813)=10.188$ , $p=0.04^*$ , $\phi=0.112$	$\chi^2(4, N=813)=1.498$ , $p=0.83$ , $\phi=0.043$
Note: * $p<0.01$						

### Results: odds ratios

Table 8.18 shows the odds ratios for sexual orientation, prostate cancer status, partnership status and outcome measures (95% CI). Where odds ratios in Table 8.18 are  $<1$ , values have been inverted for brevity. In the interpretation below, the term ‘cancer’ refers only to ‘prostate cancer’.

### Appearance evaluation

#### *Straight/gay*

Gay men were 1.83 (CI 1.28–2.59) times more likely to have a low appearance evaluation score compared with that of straight men.

#### *No prostate cancer: straight/gay*



Gay men without prostate cancer were 2.02 (CI 1.35–3.03) times more likely to have a low appearance evaluation score compared with that of straight men without prostate cancer.

## Urinary function

### *No prostate cancer/prostate cancer*

Men with prostate cancer were 1.96 (CI 1.35–2.84) times more likely to have low urinary function compared with that of men without prostate cancer.

### *Straight: No prostate cancer/prostate cancer*

Straight men with prostate cancer are 2.15 (CI 1.40–3.30) times more likely to have low urinary function compared with that of straight men without prostate cancer.

**Table 8.19: Odds ratios for sexual orientation, prostate cancer status, partnership status and outcome measures (95% CI)**

	Appearance evaluation (Low/high)	Health evaluation (Low/high)	Health orientation (Low/high)	Self- esteem (Low/high)	Urinary function (Low/high)	Sexual function (Low/high)
Straight/Gay	<b>0.55 (CI: 0.39–0.78)</b>	0.65 (CI: 0.35–1.19)	0.98 (CI: 0.56–1.71)	0.72 (CI: 0.49–1.05)	1.36 (CI: 0.91–2.04)	<b>2.40 (CI: 1.75–3.28)</b>
No cancer/Cancer	1.34 (CI: 0.92–1.97)	0.85 (CI: 0.45–1.59)	1.34 (CI: 0.75–2.42)	1.20 (CI: 0.81–1.79)	<b>0.51 (CI: 0.35–0.74)</b>	<b>0.06 (CI: 0.04–0.09)</b>
No partner/Has partner	1.59 (CI: 0.72–3.52)	1.15 (CI: 0.31–4.13)	2.40 (CI: 0.79–7.31)	1.55 (CI: 0.68–3.54)	0.65 (CI: 0.29–1.49)	1.73 (CI: 0.58–5.18)
Cancer: Straight/ Gay	1.28 (CI: 0.42–3.90)	0.34 (CI: 0.10–1.12)	1.91 (CI: 0.24– 15.04)	1.62 (CI: 0.47–5.65)	2.11 (CI: 0.70–6.33)	1.02 (CI: 0.33–3.12)
No cancer: Straight/Gay	<b>0.50 (CI: 0.33–0.74)</b>	0.69 (CI: 0.33–1.45)	1.00 (CI: 0.54–1.85)	0.65 (CI: 0.42–1.00)	0.95 (CI: 0.59–1.53)	1.20 (CI: 0.81–1.77)
Gay: No cancer/Cancer	2.45 (CI: 0.82–7.33)	0.42 (CI: 0.13–1.36)	2.42 (CI: 0.31– 18.80)	2.36 (CI: 0.69–8.14)	1.04 (CI: 0.34–3.17)	<b>0.05 (CI: 0.02–0.16)</b>
Straight: No cancer/Cancer	0.95 (CI: 0.60–1.48)	0.86 (CI: 0.40–1.88)	1.27 (CI: 0.66–2.45)	0.95 (CI: 0.60–1.51)	<b>0.47 (CI: 0.30–0.72)</b>	<b>0.06 (CI: 0.04–0.10)</b>
Numbers in bold are statistically significant at $\leq p .05$						

## **Sexual function**

### *Straight/gay*

Straight men were 2.40 (CI 1.75–3.28) times more likely to have a low sexual function compared with that of gay men.

### *No prostate cancer/prostate cancer*

Men with prostate cancer are 17.54 (CI 11.77–26.32) times more likely to have a low sexual function compared with men without prostate cancer

### *Gay: No prostate cancer/prostate cancer*

Gay men with prostate cancer are 19.23 (CI 6.37–58.82) times more likely to have a low sexual function compared with gay men without prostate cancer.

### *Straight: No prostate cancer / prostate cancer*

Straight men with prostate cancer are 16.39 (CI 10.42–25.64) times more likely to have a low sexual function compared with straight men without prostate cancer.

Results: Gay men in the study group who had surgery as their primary prostate cancer treatment (n=19) were age and primary treatment (surgery) matched with a group of straight men (n=19). No statistical differences were found in the age matched urinary function, sexual function, health evaluation, appearance evaluation or self-esteem between gay and straight men with prostate cancer.

## **REGRESSION ANALYSIS**

**Table 8.16 Adjusted R<sup>2</sup> values for outcome variables by regression analysis**

Outcome Variable	Adjusted R <sup>2</sup> Value
Health evaluation	0.0065
Health orientation	0.0285
Self esteem	0.0317
Urinary function	0.0210
Sexual function	0.0713
Appearance evaluation	0.0048

Regression analysis using the STATA statistical package showed that — after controlling for prostate cancer diagnosis, sexual orientation, age, education and income levels — gay men report statistically lower self-esteem, appearance evaluation and health evaluation than straight men. However, this effect was not observed in relation to health orientation, sexual function or urinary function.

## **Discussion**

The present cross-sectional study was designed to investigate the relationship between sexual orientation and prostate cancer diagnosis with regard to self-esteem, body image, urinary function and sexual function in Australian men. No significant difference in measures of body image (appearance evaluation, health evaluation, and health orientation), self-esteem, sexual function and urinary function were found between gay and straight men with a diagnosis of prostate cancer. These findings are counter-intuitive to the research literature of gay sexuality in other health contexts where depression in gay men with a prostate cancer was found to be higher than in the population norms (20). The results of this current study identified differences with respect to the diagnosis of prostate cancer rather than to differences attributable to sexual orientation. As

expected, men without prostate cancer reported greater urinary and sexual function than men with prostate cancer (21) (22).

Hart et al. suggested that studies of health outcomes in relation to prostate cancer and sexual orientation should entail a treatment matched sample of gay and straight men (23). This suggestion was followed by matching surgery as the primary prostate cancer treatment matched with age for gay (n=19) and straight (n=19) men. No significant differences in outcome variables were noted. There were insufficient numbers available to match when active surveillance was the primary treatment.

Men with prostate cancer also reported greater health orientation and self-esteem than healthy men. Health orientation is concerned with the extent of investment in a physically healthy lifestyle (with higher scorers indicative of greater health consciousness and desire to lead a healthier lifestyle), the result supports the view that men with prostate cancer are more conscious of their health issues compared with men who consider themselves to be prostate cancer-free and healthy. Increased self-esteem in men with prostate cancer may be due to the focused support from family, friends, associates and health professionals at the time of diagnosis and/or treatment. The seriousness of a prostate cancer diagnosis might also allow minor life stressors to be cast aside thereby allowing a focus on one's own health and psychological well-being, resulting in increased self-esteem. The absence of a significant difference in self-esteem between gay and straight men with prostate cancer was an interesting finding and is in contrast to expectations, particularly when the findings show significantly lower self-esteem for gay men without a prostate cancer diagnosis compared with straight men without a diagnosis.

Corboz et al. acknowledged anxiety and depression as important negative effects of homophobia and heterosexism influencing the mental health of non-heterosexual people (24). For gay men, the additional burden of a prostate cancer diagnosis may increase these psychological effects, which may result in lower self-esteem and body image outcomes. However, for gay men with a diagnosis of prostate cancer, results of self-esteem and body image were not significantly different from those of straight men with prostate cancer.

## **Limitations and future research**

This exploratory study may be limited by the low sample size of gay men with a diagnosis of prostate cancer. The total number of respondents in the study with a diagnosis of prostate cancer was 255 of whom 28 were gay men. The study findings were obtained from primarily Caucasian men in Australia and may not be generalisable to men in other countries, ethnicities and cultures (e.g., indigenous Australians). Globally different health systems and laws concerning gay sexual practice may influence the self-esteem and body image outcomes investigated in this study. The cross sectional nature of the study and the self-selected nature of the sample were further limitations.

The age of study participants was not evenly distributed. The difference in current age between men diagnosed with prostate cancer (gay men = 64.5 years, straight men= 66.42 years) and those without a diagnosis (gay men= 46.8 years, straight men= 49.93 years) was approximately 17 years. Such disparity was not ideal as the data indicates a significant correlation between age and four of the outcome variables (self-esteem, health orientation, urinary function and sexual function).

For those men adopting active surveillance, the numbers in each group were too low for statistical comparisons to be completed.

Comparison with other health outcome studies is problematic due to a lack of research in the area of prostate cancer and sexual orientation interaction (20). It is suggested that all future prostate cancer studies include self-identification of sexual orientation as a standard protocol.

## **Conclusion**

This study was designed to investigate prostate cancer by considering sexual orientation and produced a unique data set from respondents who are difficult to access. A range of body image and self-esteem factors was explored across a large sample of gay and straight men, with and without a prostate cancer diagnosis, together with assessment of urinary and sexual function.

Six study outcomes provided an in-depth insight concerning the wellbeing of both gay and straight men with prostate cancer. Higher self-esteem associated with a prostate cancer diagnosis and the absence of any significant difference in body image

(appearance evaluation, health evaluation, and health orientation), self-esteem, sexual function and urinary function between gay and straight men with prostate cancer were unexpected but important findings.

This study has provided baseline information in the newly emerging area of prostate cancer and sexual orientation.

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## **Chapter 9: Discussion and Conclusions**

This chapter provides the important connection between the three main research components of the thesis; the systematic review, the focus group study and the internet based cross sectional questionnaire study.

Issues concerned with health outcomes are described in this chapter. Functional and psychological aspects are considered in terms of treatment choice and decisional regret. The key themes of the focus group study are presented. Studies presenting a wide variation in treatment decisional regret are also included within this chapter. Issues concerned with the psychosocial impact of prostate cancer, particularly masculinity and hegemonic masculinity are considered together with the positioning of a prostate cancer diagnosis within a stigma focused theoretical framework. In the final section of this chapter the important connection between the first phase focus group study and the second phase questionnaire study is described.

Issues such as ethnicity, socioeconomic status and co-morbidity have been identified as important contributors to health related quality of life –HRQOL- which, while included in some studies, have been omitted from others (1-3). Demographic information, which has a strong bearing on HRQOL outcomes, has been incomplete in all but a few studies. The work by Ramsey et al suggests that care must be taken with the interpretation of results which do not fully account for the multiple factors that influence HRQOL (1).

Sexual orientation, which is a vital area for inclusion when addressing issues of health disparity, is often an important omission from the demographic information (4-7). In the study of prostate cancer, outcomes with reference to sexual orientation have received little attention (8-10). The two papers by Blank and Kleinmann strongly suggest that disparities exist when prostate cancer is viewed with the regard to of sexual orientation (11, 12). This literature has led to the current work whereby a sense of wellbeing of gay men diagnosed with prostate cancer have been investigated in terms of body image and self-esteem.

Rather than accounting solely for overall survival in prostate cancer, Aning et al suggest that functional and psychological aspects must be considered (13). As functional and psychological attributes significantly contribute to one's sense of general wellbeing; measures of these two personal attributes were included in the large questionnaire based

study as presented in this chapter. The six variable outcomes; urinary function, sexual function, self-esteem and three components of body image: appearance evaluation, health evaluation and health orientation, have been examined in the current study.

It was anticipated that these six measures of the quantitative study would clarify the role of sexual orientation with regard to a sense of wellbeing post prostate cancer diagnosis. In lieu of a validated measure of wellbeing in gay men, a commonly used instrument the Rosenberg self-esteem scale, was employed in this current study (14).

Having described the incidence, diagnosis and staging system of prostate cancer, in Chapter 2, “Prostate cancer, an introduction and treatment options” treatment and treatment side effects were discussed. For some men, there was a sense that they had made an incorrect choice when deciding on their initial prostate cancer treatment.

#### *Themes derived from the Systematic Review*

The systematic review employed the question, “How does the diagnosis of prostate cancer impact the quality of life of gay men?” and had a search time-frame from 1<sup>st</sup> December 1992 to August 2014. The systematic review produced four relevant papers (8, 25-27). The search was concerned with changes in sexual roles and quality of life for gay men (or men who have sex with men) after prostate cancer (28-31). The paper by Hart et al which reported gay men with prostate cancer as having substantial changes in sexual functioning after prostate cancer treatment and also as reporting significantly worse disease-specific and general HRQOL, fear of recurrence, and less satisfaction with their medical care than other prostate cancer samples was particularly important (28).

#### *Themes derived from the focus group study*

The key concerns of men of the first phase focus group study, as described in Chapter 7, included: emotional response to the prostate cancer diagnosis, need to access help and support, the impact of incontinence, the impact of sexual changes on identity moderated emotional state by ability to re-evaluate life, changed sexual relationships, finding the right health care professional and current needs to improve quality of care.

#### *Treatment choice and decisional regret*

While these themes can evoke decisional regret or conflict, the percentage of men expressing regret of treatment choice have produced varying results. The work by Davison indicated that 4% expressed regret over their decision to have surgery (15). The study by Diefenbach et al identified a significant increase in regret between 6 and 12 months after diagnosis although levels of decisional regret were low overall and that those treated with prostatectomy showed greater decisional regret compared to patient treated with external beam radiation or brachytherapy (p449) (16).

The lack of supporting scientific evidence of one localised prostate cancer treatment over another is an added complication in treatment choice. Absence of evidence makes the choice a high-risk decision in that once a decision is made it, is not always possible to undertake an alternate treatment (17). Despite receiving information about risks and benefits of particular treatments patients may still hold unrealistic expectations of treatment outcomes (pS38)(13). Such hopes are not necessarily eliminated by extra support time and intensive counselling (18). The study by Wittmann found that despite counselling, some men with poor pre-operative erectile function, expected improved erectile function post prostatectomy (18).

The experience of side effects, particularly that of erectile dysfunction, as presented in Chapter 2, promoted decisional regret for some men. Research by Chien's group indicated that those men with inferior psychosocial adjustment may experience higher decisional conflict and regret (19). However, Collingwood et al showed that the majority of participants were not regretful of their decision to undergo robotic-assisted laparoscopic prostatectomy (20). In contrast, the study by O'Shaughnessy showed 24.5% of study participants expressing regret regarding treatment choice (21).

#### *Neglected side effects, regret and decision-making aids*

Frey has described the neglected side effects of prostatectomy which include: orgasm-associated incontinence (OAI), urinary incontinence in relation to sexual stimulation (UISS), altered perception of orgasm, orgasm-associated pain (OAP), penile shortening and penile deformity (22). While the experience of these side effects may trigger decisional regret, such regret has been correlated with passive involvement in the decision-making process (pS41)(13). A similar finding was made by Davison who

reported the most variability and highest scores on decision regret from men who assumed a passive role in treatment decision making (15). To assist with the decision process, decision-making aids have been used. The knowledge gained by using the decision-making aids at all stages of a patient's journey minimises anxiety and reduces decisional conflict attributable to feeling uninformed (pS40) (13). Research by Aning et al suggests that while up to one third of patients express some regret, decision-making aids engage patients to participate in decisions that involve risks and benefits' (pS40) (13).

### *Masculinity, hegemonic masculinity and stigma*

Factors contributing to the psychosocial impact of prostate cancer have been presented in chapter 3. While a number of these issues (e.g. anxiety and depression), may also be common to a diagnosis of other types of cancer, (23, 24). Some issues, such as masculinity and hegemonic masculinity, particularly relate to prostate cancer. Hegemonic masculinity, with its implied heterosexuality and failure to recognise alternate sexual orientation, was considered to be unhelpful in positioning of prostate cancer within a stigma focused theoretical framework as described in chapter 4. Stigma was viewed with regard to health, cancer, sexual orientation, age and prostate cancer. Stigma management was presented in terms of the impact of cancer in general and on prostate cancer in particular.

Overall, the findings of the focus group study indicated that while prostate cancer impacted significantly on the lives of these men and although some gained a positive perspective and experienced a sense of empowerment, the main concerns of the group were: the need to access help and support, the need to find a suitable health care professional, the impact of incontinence, the impact of changed sexual identity and changed sexual relationships, (27).

The above published paper by Thomas et al states that 'areas of disquiet suggest that the psychological impact of this disease may be quite significant over an extended time-frame' (p522)(27). Further investigation has been undertaken in the quantitative study of Chapter 8 where participants were grouped according to self-identified sexual orientation and prostate cancer status.

The study by O'Shaughnessy et al used focus groups of men (n=115) to provide "insight into the experiences of prostate cancer in areas such as sexual function and relationships" concluded that "men are not able to clearly identify the challenges prostate cancer brings especially changes to their masculinity" (p3492)(21). The sexual orientation of the focus groups in the O'Shaughnessy study remains unknown. The prostate cancer treatment types for the O'Shaughnessy study included: active surveillance, prostatectomy, radiotherapy and hormone therapy. An important issue of the O'Shaughnessy study concerned the time elapsed since initial prostate cancer treatment with 74.8% of the study cohort being greater than three months post treatment. "Key secondary themes that were related to sexuality and sexual function included emotional responses to the cancer, physical responses to cancer and the need for supportive care" (21). A significant part of the secondary themes concerned feelings related to loss and changes to masculinity generated by sexual dysfunction (21).

The findings of the O'Shaughnessy study concerning needs of men post prostate cancer diagnosis connect closely with the first phase focus group research as presented in chapter 7 (21). The needs of the focus group of gay men as described in the qualitative study were found to relate to: emotional responses to a diagnosis of prostate cancer, accessing help and support, the impact of incontinence, the impact of sexual changes on identity, a re-evaluation of life, changed sexual relationships, the need to find the most suitable health care professionals and identification of current needs to improve quality of care.

As the identified needs of the focus group of Chapter 7 as listed above were similar to those of the O'Shaughnessy study, further investigation was undertaken via the online cross sectional study of chapter 8 to determine whether these needs were mirrored in the alignment of self-esteem and body image outcomes according to sexual orientation further investigation was undertaken via the second phase large quantitative study of Chapter 8. If the self-esteem and body image of the gay men of the quantitative study were found to be identical with that of the straight group, this would suggest that the post prostate cancer diagnosis journey is independent of sexual orientation. The corollary being that differences detected in self-esteem and body image would suggest that the experience of prostate cancer was different for the gay and straight men.

Young men are more often more open about their sexuality than those gay and bisexual men typically diagnosed with prostate cancer later in life (12). Such reserve of these older men may preclude them from discussing their quality of life expectations with the primary care provider (12). This situation exacerbates the stress which is already high at this difficult time (32). Hart et al have shown that gay and bisexual men treated for prostate cancer have a lower quality of life than other prostate cancer survivors (33). While such a result indicates that the gay and bisexual group may be in need of greater supportive care, it might also suggest that there are other issues, such as altered gay sexual identity which may need to be addressed within the supportive care program.

For all gay men with a diagnosis of prostate cancer compared with all straight men with a diagnosis of prostate cancer, in the large second phase questionnaire based study of chapter (8), no significant differences were observed in *appearance evaluation, health evaluation, health orientation, self-esteem, urinary function* and *sexual function* scores of gay and straight men with prostate cancer.

The quantitative study indicates that while the pre-diagnosis levels of body image and self-esteem are non- identical for gay and straight men, such differences are absent in these variables post prostate cancer diagnosis. The initial difference in pre-diagnosis scores of body image and self-esteem for gay and straight men and the equivalence of post-diagnosis scores suggests that the path navigated to achieve equivalence of post diagnosis scores is different. This difference suggests that the prostate cancer journey/trajectory from “undiagnosed” to “diagnosed”, may be different for gay and straight men, but that they share much in common in responding to the threat of prostate cancer.

The research by Kleinmann et al suggests that certain subgroups of men, as per ethnicity or men who have sex with men MSM, are particularly susceptible to reductions in quality of life during their prostate cancer experience (12). Research by Orsi suggests that the experiences of gay men diagnosed with prostate cancer as seen in terms of social relationships, sexuality and interaction with the health care community are different from the experiences of straight men similarly diagnosed (34).

Gay and bisexual men may feel uncomfortable about disclosing their sexual orientation, “coming out” to either their primary healthcare provider or specialist urologist/

oncologist (12). As gay men navigate the heterosexually-dominated world of prostate cancer treatment, disclosure of sexual orientation can be a difficulty (35). Researchers have shown that in order to overcome the resulting disparities regarding the trajectory of prostate cancer, gay and bisexual men must feel safe and welcomed when seeking health care (36). A sense of safety and welcoming attitude may be factors which were overlooked by Cockle, Hearne and Faithfull in their extensive review of unmet supportive care needs of prostate cancer survivors (37). When there is a perception of hetero-normative attitude in the health care system, a feeling of care may not be evident (8).

### **Limitations**

Decisional regret was not measured due to constraints regarding the need to maximize responses and therefore reduce the time taken to complete the questionnaire, which took approximately 12 minutes. Addition of the decisional regret measure would have contributed important information, yet it would also add to the time burden for completion of the original questionnaire. The Short-form Supportive Care Needs Survey, which covers five domains of need (health system and information, psychological, physical, care and support and sexuality needs) as used by Hodgkinson in the “Breast cancer survivors’ supportive care needs 2-10 years after diagnosis” study would have been a suitable tool to employ in the current survey (38).

The small number of gay men of the study with a diagnosis of prostate cancer who had experienced surgery (n=19) made comparison with the equivalent straight group statistically impossible.

### **Summary and conclusion**

This study has shown that the experience of gay and straight men following a diagnosis of prostate cancer is not identical although that these men have much in common.

The absence of any significant differences in body image including appearance evaluation (despite differences in gay and straight men without prostate cancer), health evaluation, health orientation, self-esteem, urinary function and sexual function (although these two factors were significantly lower in gay men with prostate cancer compared with those without) were unexpected but important findings. This study has

provided baseline information in the newly emerging area of prostate cancer and sexual orientation.

The areas of difference between gay and straight men with and without prostate cancer provide an opportunity for more focused counselling in the future. These include the higher health orientation scores associated with a prostate cancer diagnosis in gay men, and the interesting and different trends in most variables between both gay men with and without prostate cancer and straight men with and without prostate cancer.

Gay and straight men with prostate cancer are similar in many respects, but their journey to their similarity compared with their prostate-cancer-free counterparts is apparently different, and would benefit from more exploration.

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## **Appendices**

### **Appendix 1: Focus group study**

- 1.1 Ethics approval documents
- 1.2 Focus group study participant consent form
- 1.3 Focus group theme list

### **Appendix 2: Internet based cross sectional questionnaire study**

- 2.1 Ethics approval documents
- 2.2 Internet based cross sectional questionnaire study: Participant information statement, consent sheet and data collection instrument 2.3

### **Appendix 3: Data handling tables**

- 3.1: Matching sexual function survey monkey questions to EPIC scale
- 3.2 Standardisation of sexual function values
- 3.3: Matching urinary function survey monkey questions to EPIC scale
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### **Appendix 4: Poster presentations from the PhD**

- 4.1: Poster presented of systematic review as part of the PhD program
- 4.2: Poster presented as part of the PhD program



## Appendix 1.1: Focus group study: Ethics approval documents



RESEARCH SERVICES

### MEMORANDUM

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**To:** Dr. Priscilla Robinson, School of Human Biosciences/Public Health, FHS  
Mr. Christopher Thomas, School of Human Biosciences/Public Health, FHS

**From:** Secretary, La Trobe University Human Ethics Committee

**Subject:** Review of Human Ethics Committee Application No. 11-092

**Title:** An e-focus group for gay and bisexual men who have been diagnosed with prostate cancer

**Date:** 29 February 2012

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Thank you for your recent correspondence in relation to the research project referred to above. The project has been assessed as complying with the *National Statement on Ethical Conduct in Human Research*. I am pleased to advise that your project has been granted ethics approval and you may commence the study.

**The project has been approved from the date of this letter until 31 March 2012.**

*Please note that your application has been reviewed by a sub-committee of the University Human Ethics Committee (UHEC) to facilitate a decision about the study before the next Committee meeting. This decision will require ratification by the full UHEC at its next meeting and the UHEC reserves the right to alter conditions of approval or withdraw approval. You will be notified if the approval status of your project changes. The UHEC is a fully constituted Ethics Committee in accordance with the National Statement on Ethical Conduct in Research Involving Humans-March 2007 under Section 5.1.29.*

The following standard conditions apply to your project:

- **Limit of Approval.** Approval is limited strictly to the research proposal as submitted in your application while taking into account any additional conditions advised by the UHEC.
- **Variation to Project.** Any subsequent variations or modifications you wish to make to your project must be formally notified to the UHEC for approval in advance of these modifications being introduced into the project. This can be done using the appropriate form: *Ethics - Application for Modification to Project* which is available on the Research Services website at [http://www.latrobe.edu.au/research-services/ethics/HEC\\_human.htm](http://www.latrobe.edu.au/research-services/ethics/HEC_human.htm). If the UHEC considers that the proposed changes are significant, you may be required to submit a new application form for approval of the revised project.
- **Adverse Events.** If any unforeseen or adverse events occur, including adverse effects on participants, during the course of the project which may affect the ethical acceptability of the project, the Chief Investigator must immediately notify the UHEC Secretary on telephone (03) 9479 1443. Any complaints about the project received by the researchers



must also be referred immediately to the UHEC Secretary.

- **Withdrawal of Project.** If you decide to discontinue your research before its planned completion, you must advise the UHEC and clarify the circumstances.
- **Annual Progress Reports.** If your project continues for more than 12 months, you are required to submit an *Ethics - Progress/Final Report Form* annually, **on or just prior to 12 February**. The form is available on the Research Services website (see above address). Failure to submit a Progress Report will mean approval for this project will lapse. An audit may be conducted by the UHEC at any time.
- **Final Report.** A Final Report (see above address) is required within six months of the completion of the project or by **30 September 2012**.

If you have any queries on the information above or require further clarification please contact me through Research Services on telephone (03) 9479-1443, or e-mail at: [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au).

On behalf of the University Human Ethics Committee, best wishes with your research!

Ms Barbara Doherty  
Administrative Officer (Research Ethics)  
University Human Ethics Committee  
Research Compliance Unit / Research Services  
La Trobe University Bundoora, Victoria 3086  
P: (03) 9479 – 1443 / F: (03) 9479 - 1464  
[http://www.latrobe.edu.au/research-services/ethics/HEC\\_human.htm](http://www.latrobe.edu.au/research-services/ethics/HEC_human.htm)

## Appendix 1.2: Focus group study: Participant consent form



### Consent Statement

School of Human Biosciences and Public Health

La Trobe University

Melbourne, Vic 3086

### AN E-FOCUS GROUP FOR GAY AND BISEXUAL MEN WHO HAVE BEEN DIAGNOSED WITH PROSTATE CANCER

#### *Consent Statement*

*I have read and understood the Participation Information Page and any questions I have asked have been answered to my satisfaction. I have read and understood the “Eligibility Criteria” section on the Participation Information Page. I acknowledge that I meet the eligibility criteria as listed for participation in the study. I understand the research, my participation in it and what this involves. I comprehend the implications of the research and what will be done with the data. I agree to participate in the project, realising that I may withdraw at any time. I agree that research data provided by me or with my permission during the project may be included in a thesis, presented at conferences and published in journals on the condition that neither my name nor any other identifying information is used.*

You may withdraw from the e-focus group at any time and this will not affect your treatment, relationship with Cancer Council Victoria, Prostate Cancer Foundation of Australia or a related support group.

Please e-mail me at [researcherpca@hotmail.com](mailto:researcherpca@hotmail.com) to let me know that you give consent to be a participant in this study.

Thank you for your consideration of this project,

Chris Thomas

### Appendix 1.3: Focus group study: Focus group theme list

#### Online focus group questions:

1) How did the diagnosis of Prostate Cancer immediately affect you? (e.g. gave up work, psychological issues)

Have you had side effects from prostate cancer treatment? If so, what were they and how did you cope with them?

How has your diagnosis/treatment of prostate cancer affected your daily life? (eg stopped swimming, no longer going out).

What has been your experience from the gay community in relation to your diagnosis of prostate cancer?"

3) Since your diagnosis, do you see yourself differently? Does your body seem different to you? If so, in what ways?

3b) Do you think you have changed as a gay man? Do other gay men treat you differently?

2) What did you find helpful (and supportive) following a diagnosis and treatment of prostate cancer?

2b) If you were to go through this prostate cancer experience again what would you find useful or supportive in helping you cope with or adjust to life after prostate cancer?

## Appendix 2.1 : Internet based cross sectional questionnaire study: Ethics approval documents



RESEARCH SERVICES

### MEMORANDUM

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**To:** Dr Priscilla Robinson, School of Human Biosciences and Public Health, FHS  
Mr. Christopher Thomas, School of Human Biosciences and Public Health, FHS

**From:** Acting Secretary, La Trobe University Human Ethics Committee

**Subject:** Review of Human Ethics Committee Application No. 13-006

**Title:** Australian Men's Quality of Life and Prostate Cancer Study

**Date:** 24 April 2013

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Thank you for your recent correspondence in relation to the research project referred to above. The project has been assessed as complying with the *National Statement on Ethical Conduct in Human Research*. I am pleased to advise that your project has been granted ethics approval and you may commence the study now.

**The project has been approved from the date of this letter until 30 April 2015.**

*Please note that your application has been reviewed by a sub-committee of the University Human Ethics Committee (UHEC) to facilitate a decision before the next Committee meeting. This decision will require ratification by the UHEC and it reserves the right to alter conditions of approval or withdraw approval at that time. You will be notified if the approval status of your project changes. The UHEC is a fully constituted Ethics Committee in accordance with the National Statement under Section 5.1.29.*

The following standard conditions apply to your project:

- **Limit of Approval.** Approval is limited strictly to the research proposal as submitted in your application while taking into account any additional conditions advised by the UHEC.
- **Variation to Project.** Any subsequent variations or modifications you wish to make to your project must be formally notified to the UHEC for approval in advance of these modifications being introduced into the project. This can be done using the appropriate form: *Ethics - Application for Modification to Project* which is available on the Research Services website at [http://www.latrobe.edu.au/research-services/ethics/HEC\\_human.htm](http://www.latrobe.edu.au/research-services/ethics/HEC_human.htm). If the UHEC considers that the proposed changes are significant, you may be required to submit a new application form for approval of the revised project.
- **Adverse Events.** If any unforeseen or adverse events occur, including adverse effects on

participants, during the course of the project which may affect the ethical acceptability of the project, the Chief Investigator must immediately notify the UHEC Secretary on telephone (03) 9479 1443. Any complaints about the project received by the researchers must also be referred immediately to the UHEC Secretary.

- **Withdrawal of Project.** If you decide to discontinue your research before its planned completion, you must advise the UHEC and clarify the circumstances.
- **Monitoring.** All projects are subject to monitoring at any time by the University Human Ethics Committee.
- **Annual Progress Reports.** If your project continues for more than 12 months, you are required to submit an *Ethics - Progress/Final Report Form* annually, **on or just prior to 12 February**. The form is available on the Research Services website (see above address). Failure to submit a Progress Report will mean approval for this project will lapse.
- **Auditing.** An audit of the project may be conducted by members of the UHEC.
- **Final Report.** A Final Report (see above address) is required within six months of the completion of the project or by **31 October 2015**.

If you have any queries on the information above or require further clarification please contact me through Research Services on telephone (03) 9479-1443, or e-mail at: [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au).

On behalf of the University Human Ethics Committee, best wishes with your research.

Ms. Lynda Boldt

Administrative Officer – Research  
Acting Secretariat – University Human Ethics Committee  
Research Compliance Unit  
Research Services | La Trobe University | Bundoora 3086  
T: 03 9479 3589 | F: 03 9479 1464 | E: [l.boldt@latrobe.edu.au](mailto:l.boldt@latrobe.edu.au) | <http://latrobe.edu.au/research-services/>  
[http://www.latrobe.edu.au/research-services/ethics/HEC\\_human.htm](http://www.latrobe.edu.au/research-services/ethics/HEC_human.htm)

## Appendix 2.2 and Appendix 2.3: Internet based cross sectional questionnaire study: Participant information statement, consent sheet and data collection instrument

<b>Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey</b>	
<b>Participation Information Statement.</b>	
	<p>This study looks at the health and well-being of all men living in Australia who are 30 years of age or older.</p> <p>What is this study about?</p> <p>This study is being conducted to investigate the impact of a diagnosis of prostate cancer. Note, the study will consider body image and self-esteem of men in the presence or absence of a prostate cancer diagnosis. Therefore your answers to the study survey are needed whether or not you have been diagnosed with prostate cancer.</p> <p>Why is this study being done?</p> <p>Comparing body image and self-esteem of those who have experienced prostate cancer with those who have not, may highlight important issues requiring attention at the time of diagnosis, at the time of treatment and for many years post prostate cancer diagnosis.</p> <p>How will the study be done?</p> <p>Men over the age of 30 years are requested to complete a questionnaire concerning body image. The questionnaire will start by asking you some demographic information (e.g. What is your post code?) followed by some questions relating to your sense of body image. Those men who have had a diagnosis of prostate cancer will be asked to complete some additional questions.</p> <p>Although the potential risks from participation in the study are minimal some men may find aspects of the questionnaire confronting and therefore options for support have been provided at the end of the survey. (See final page of survey "Debriefing Sheet")</p> <p>What will happen with the results?</p> <p>The results will be summarised and published in medical journals and other publications and they will also be presented at various Australian and international conferences. The results from this study will also be published as part of a PhD thesis. Only group results will be presented and no individual will be able to be identified.</p> <p>What benefits will participants get from being in this study?</p> <p>While participants may gain insight into their own health, information obtained in this study may provide direction for best practice in the treatment of men diagnosed with prostate cancer in the future.</p> <p>Eligibility Criteria</p> <p>In order to participate in this study, participants must be male and 30 years of age or older living in Australia with the ability to read and write English.</p> <p>There are no disadvantages, penalties or adverse consequences for not participating in this research. By returning the questionnaire it is implied that you have consented to participate in this study. As the questionnaires have not been identified in order to ensure confidentiality, once returned the data cannot be withdrawn nor separated from that of other participants.</p>
<b>Participation Information Statement</b>	
	<p>The Questionnaire.</p> <p>The questionnaire, which will take less than 10 minutes to complete, will be submitted using the Survey Monkey research website. Submitted questionnaires are received and tabulated via the Survey Monkey site. The information</p>



## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

from all questionnaires is automatically combined in Survey Monkey resulting in an overall total response. Only the researchers involved with this study will have access to the data received from Survey Monkey.

The source of a completed questionnaire remains unknown to the investigator and is in no way identifiable. That is, when you complete and submit your questionnaire using Survey Monkey, your e-mail address will not be visible or available to the investigators. Therefore your privacy is maintained.

A participant can only withdraw from the study before submission of the questionnaire.

I would greatly appreciate your participation in this survey.

Regards,  
Chris Thomas  
Study Coordinator

### Contact details

For further information on this research project, please do not hesitate to contact the study investigators:

1. Christopher Thomas [c4thomas@students.latrobe.edu.au](mailto:c4thomas@students.latrobe.edu.au)  
PhD student, La Trobe University, School of Human Biosciences and Public Health, Faculty of Health Sciences.

2. Dr Priscilla Robinson [priscilla.robinson@latrobe.edu.au](mailto:priscilla.robinson@latrobe.edu.au)  
Supervisor, La Trobe University, School of Human Biosciences and Public Health,  
Faculty of Health Sciences.

3. Dr Addie Wootten [addie.wootten@apcr.org.au](mailto:addie.wootten@apcr.org.au)  
Co- Supervisor, Australian Prostate Cancer Research.

This study has been approved by La Trobe University, Human Ethics Committee. UHEC reference number: 13-006

If you have any complaints or queries that the investigator has not been able to answer to your satisfaction, you may contact:

The Secretary, Human Ethics Committee, Research Services, La Trobe University, Victoria, 3086 Phone: (03) 9479 1443 e-mail [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au)

## Consent Statement

I have read and understood the Participation Information Statement and any questions I have asked have been answered to my satisfaction.

I have read and understood the "Eligibility Criteria" section on the Participation Information Statement. I acknowledge that I meet the eligibility criteria as listed for participation in the study. I understand the research, my participation in it and what this involves. I comprehend the implications of the research and what will be done with the data. I agree to participate in the project, realising that I may withdraw at any time prior to the submission of the questionnaire.

I agree that research data provided by me or with my permission during the project may be included in a thesis, presented at conferences and published in journals on the condition that neither my name nor any other identifying information is used.

## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

I understand that by submitting the online survey I am giving consent to be a participant within this study.

### \*Was the invitation to complete this survey received:

- ☐ via e-mail from a friend?
- ☐ via e-mail from the study coordinator (Chris Thomas)?
- ☐ via facebook from a friend?
- ☐ via facebook from the study coordinator (Chris Thomas)?
- ☐ via word of mouth?
- ☐ other?

### \*I am a male, 30 years of age or older, living in Australia

- ☐ Yes
- ☐ No

## Section 1

As this survey is looking at the health of Australian men over a wide age range, there may be some aspects of ill-health which don't apply to yourself. Simply answer each question as it best applies to you.

### \*What is your age?

### \*What is your postcode?

### \*Ethnicity

Do you self-identify as (Please select one only)

- ☐ Caucasian
- ☐ Aboriginal or Torres Strait Islander
- ☐ Asian
- ☐ African
- ☐ Other

If other (please specify)

## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

### \*Partnership Status

What is your partnership status?

- ☐ Never married/Single
- ☐ Married
- ☐ Divorced or separated
- ☐ Widowed
- ☐ Living with partner (female)
- ☐ Living with partner (male)

### \*Sexual Orientation

Do you self-identify as (Please select one only)

- ☐ Straight (Heterosexual)
- ☐ Gay (Homosexual)
- ☐ Bisexual
- ☐ Transgender
- ☐ Other

If other (please specify)

### \*What is your highest level of education?

- ☐ Primary school
- ☐ Secondary school
- ☐ Certificate or Diploma
- ☐ University or college degree
- ☐ Post-graduate

What is your total household income per year?

- ☐ less than \$25,000
- ☐ between \$25,001 and \$50,000
- ☐ between \$50,001 and \$75,000
- ☐ between \$75,001 and \$100,000
- ☐ between \$100,001 and \$125,000
- ☐ greater than \$125,000

## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

This questions asks about different medical conditions you may have.

For each conditon answer yes or no as to whether a doctor has ever told you that you had the condition.

Has doctor ever told you that you had.....?

	Yes	No
Arthritis or rheumatism	<input type="radio"/>	<input type="radio"/>
Diabetes or high blood sugar	<input type="radio"/>	<input type="radio"/>
Inflammatory bowel disease, colitis or Crohn's disease.	<input type="radio"/>	<input type="radio"/>
Bleeding from stomach ulcer	<input type="radio"/>	<input type="radio"/>
Asthma, Chronic lung disease, bronchitis or emphysema.	<input type="radio"/>	<input type="radio"/>
Heart failure	<input type="radio"/>	<input type="radio"/>
AIDS defining illness	<input type="radio"/>	<input type="radio"/>
Kidney diseese	<input type="radio"/>	<input type="radio"/>
Stroke or brain haemorrhage.	<input type="radio"/>	<input type="radio"/>
High blood pressure	<input type="radio"/>	<input type="radio"/>
Heart attack or myocardial infarction	<input type="radio"/>	<input type="radio"/>
Chest pain or angina	<input type="radio"/>	<input type="radio"/>
Liver disease or cirrhosis	<input type="radio"/>	<input type="radio"/>
Depression or anxiety	<input type="radio"/>	<input type="radio"/>
Any type of Cancer ( other than Prostate Cancer or non-melanoma skin cancer)	<input type="radio"/>	<input type="radio"/>

If you have had Cancer (other than Prostate Cancer or non-melanoma skin cancer) please list the type(s)

**\*Would you say that your health is usually.....**

- ☐ Excellent  
☐ Good  
☐ Fair  
☐ Poor

## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

**\*Has a close male relative of yours ever been diagnosed with prostate cancer?**

- ☐ No
- ☐ Father
- ☐ Brother
- ☐ Son
- ☐ Uncle (Father's brother)
- ☐ Uncle (Mother's brother)
- ☐ First Cousin
- ☐ Male Partner

**\*Have you ever had a test for prostate cancer?**

- ☐ Yes
- ☐ No
- ☐ Not sure

**\*Have you ever been diagnosed with prostate cancer?**

- ☐ Yes
- ☐ No

**What was your age at prostate cancer diagnosis?**

**What was your PSA at the time of diagnosis?**

**What was your Gleason score at the time of diagnosis?**

**In the time from when you were first diagnosed with prostate cancer up until today, has your income:**

- ☐ Increased
- ☐ Remained the same
- ☐ Decreased

## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

**What was your primary (first) treatment for your prostate cancer?**

**(You may tick more than one box if your first treatment was a combination of any of the treatments listed below)**

- ☐ Surgery (robotic, laparoscopic, open)
- ☐ Radiotherapy
- ☐ Hormone Therapy
- ☐ Brachytherapy (seeds)
- ☐ HIFU (High Intensity Focused Ultrasound)
- ☐ Cryotherapy (freezing)
- ☐ Active Surveillance/Watchful Waiting
- ☐ Other

If other (please specify)

**If your first treatment was not Active Surveillance/Watchful waiting, how many weeks were there from your prostate cancer diagnosis until your first treatment?**

**Following your initial treatment, have you had any secondary (second) treatment for your prostate cancer?**

- ☐ Yes
- ☐ No

**If you answered "Yes" to the question above, what secondary treatment did you have? (Tick all that apply)**

- ☐ Surgery (robotic, laparoscopic, open)
- ☐ Radiotherapy
- ☐ Hormone Therapy
- ☐ Brachytherapy (seeds)
- ☐ HIFU (High Intensity Focused Ultrasound)
- ☐ Cryotherapy (freezing)
- ☐ Other

If other (please specify)

## Section 2 SEXUAL FUNCTION

This section is about your current sexual function and sexual satisfaction.

Please consider your answers in regard to the LAST FOUR weeks only.

**How would you rate each of the following during the last 4 weeks?**

	Very poor to none	Poor	Fair	Good	Very good
Your level of sexual desire?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your ability to have an erection?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your ability to reach orgasm (climax)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**How would describe the usual QUALITY of your erections during the last 4 weeks?**

- ☐ None at all
- ☐ Not firm enough for any sexual activity
- ☐ Firm enough for masturbation and foreplay only
- ☐ Firm enough for intercourse

**How would you describe the FREQUENCY of your erections during the last 4 weeks?**

- ☐ I never had an erection when I wanted one
- ☐ I had an erection LESS THAN HALF the time I wanted one
- ☐ I had an erection ABOUT HALF the time I wanted one
- ☐ I had an erection MORE THAN HALF the time I wanted one
- ☐ I had an erection WHENEVER I wanted one

## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

**How often have you awakened in the morning or night with an erection during the last 4 weeks?**

- ☐ Never
- ☐ Less than once a week
- ☐ About once a week
- ☐ Several times a week
- ☐ Daily

**During the last 4 weeks, how often did you have any sexual activity?**

- ☐ None at all
- ☐ Less than once a week
- ☐ About once a week
- ☐ Several times a week
- ☐ Daily

**During the last 4 weeks, how often did you have sexual intercourse?**

- ☐ Not at all
- ☐ Less than one a week
- ☐ About once a week
- ☐ Several times a week
- ☐ Daily

**Overall, how would you rate your ability to function sexually during the last 4 weeks?**

- ☐ Very poor
- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Very good

**How big a problem during the last 4 weeks, if any, has each of the following been for you?**

	No problem	Very small problem	Small problem	Moderate problem	Big problem
Your level of sexual desire	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your ability to have an erection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your ability to reach an orgasm	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

**Overall, how big a problem has your sexual function or lack of sexual function been for you during the last 4 weeks?**

- ☐ No problem
- ☐ Very small problem
- ☐ Small problem
- ☐ Moderate problem
- ☐ Big problem

### Section 3 Urinary Function

This section is about your urinary habits. Please consider ONLY THE LAST FOUR WEEKS

**Over the last four weeks, how often have you leaked urine?**

- ☐ More than once a day
- ☐ About once a day
- ☐ More than once a week
- ☐ About once a week
- ☐ Rarely or never

**Over the past four weeks, how often have you urinated blood?**

- ☐ More than once a day
- ☐ About once a day
- ☐ More than once a week
- ☐ About once a week
- ☐ Rarely or never

**Over the past 4 weeks, how often have you had pain or burning with urination?**

- ☐ More than once a day
- ☐ About once a day
- ☐ More than once a week
- ☐ About once a week
- ☐ Rarely or never

## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

**Which of the following best describes your urinary control during the last 4 weeks?**

- ☐ No urinary control whatsoever
- ☐ Frequent dribbling
- ☐ Occasional dribbling
- ☐ Total control

**How many pads per day did you usually use to control leakage during the last 4 weeks?**

- ☐ None
- ☐ One pad per day
- ☐ Two pads per day
- ☐ 3 or more pads per day

**How big a problem, if any, has each of the following been for you during the last 4 weeks?**

	No problem	Very small problem	Small problem	Moderate problem	Big problem
Dripping or leaking urine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pain or burning on urination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bleeding with urination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Weak urine stream or incomplete emptying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Waking up to urinate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Need to urinate frequently during the day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Overall, how big a problem has your urinary function been for you during the last 4 weeks**

- ☐ No problem
- ☐ Very small problem
- ☐ Small problem
- ☐ Moderate problem
- ☐ Big problem

### Section 4 Self-Esteem

Guys, you are doing extremely well to get to this stage of the questionnaire, please keep going right to the end....just a few more minutes and you will be done :)

## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

**I feel that I am a person of worth, at least on an equal plane with others.**

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

**I feel that I have a number of good qualities**

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

**All in all, I am inclined to feel that I am a failure**

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

**I am able to do things as well as most other people.**

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

**I feel I do not have much to be proud of.**

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

**I take a positive attitude toward myself.**

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

**On the whole, I am satisfied with myself.**

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

**I wish I could have more respect for myself.**

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

**I certainly feel useless at times.**

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

**At times I think I am no good at all.**

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

### Section 5 Body Image

The following part of the survey contains a series of statements about how men might think, feel or behave.

There are no right or wrong answers.

Please indicate the extent to which each statement applies to you personally.

**My body is sexually appealing**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

### **I am in control of my health**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

### **I know a lot about things that affect my physical health**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

### **I have deliberately developed a healthy lifestyle**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

### **I like my looks just the way they are.**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

### **My health is a matter of unexpected ups and downs**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

**Good health is one of the most important things in my life.**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

**I don't do anything that I know might threaten my health**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

**Most people would consider me good-looking**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

**I am seldom physically ill.**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

**I take my health for granted.**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

**I often read books and magazines that pertain to health**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

**I like the way I look without my clothes on.**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

**From day to day, I never know how my body will feel.**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

**I make no special effort to eat a balanced and nutritious diet.**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

**I like the way my clothes fit me.**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

### **I dislike my physique.**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

### **I often feel vulnerable to sickness.**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

### **I am physically unattractive.**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

### **I know a lot about physical fitness.**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

### **I am a physically healthy person.**

- ☐ Definitely disagree
- ☐ Mostly disagree
- ☐ Neither agree nor disagree
- ☐ Mostly agree
- ☐ Definitely agree

**And finally.....**



## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

You have now come to the end of the questions.

You might now like to make some comment on this survey in general, and/or perhaps comment on men's health in Australia.

Again, many thanks for taking the time to complete this survey.

Best wishes for your future health.

Regards, Chris Thomas

### Comments

## Debriefing Sheet

Prostate cancer is a serious problem among men with the likelihood of diagnosis increasing with age.

Improving our knowledge concerning the way prostate cancer impacts on the lives of men is important.

Such knowledge will guide researchers and clinicians in the development of newer innovative strategies to reduce the impact of prostate cancer.

Your input will help contribute to the advancement of the field of prostate cancer research.

Your generosity and willingness to participate in this study are greatly appreciated.

Sometimes people find the subject matter of these questionnaires disturbing.

If answering any of these questions led you to feel distressed and you would like to speak to someone about your thoughts, please contact one of the following:

Lifeline 13 11 14

MensLine Australia 1300 78 99 78 (Telephone, Online and Video counseling services)

Beyondblue 1300 22 4636

More information concerning prostate cancer can be found at:

Prostate Cancer Foundation of Australia  
[www.prostate.org.au](http://www.prostate.org.au)

Lions Australian Prostate Cancer  
[www.prostatehealth.org.au](http://www.prostatehealth.org.au)

Better Health Channel  
[www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Prostate\\_cancer](http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Prostate_cancer)

For further information on this research project, please do not hesitate to contact me (Chris. Thomas) by email [c4thomas@students.latrobe.edu.au](mailto:c4thomas@students.latrobe.edu.au) or my supervisor from the School of Human Biosciences and Public Health: Dr Priscilla Robinson [priscilla.robinson@latrobe.edu.au](mailto:priscilla.robinson@latrobe.edu.au)

If you have any complaints or queries that the investigator has not been able to answer to your satisfaction, you may contact:  
The Secretary,

## Australian Men's Body Image, Self-Esteem and Prostate Cancer Survey

Human Ethics Committee,  
Research Services,  
La Trobe University, Victoria, 3086  
Phone: (03)9479 1443 or [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au)

### **Appendix 3: Data handling tables**

3.1: Matching sexual function survey monkey questions to EPIC scale

3.2 Standardisation of sexual function values

3.3: Matching urinary function survey monkey questions to EPIC scale

3.4: Standardisation of urinary function values

### 3.1: Matching sexual function survey monkey questions to EPIC scale

	• Sexual Function												
• Epic Item	• 56	• 57	• 58	• 59	• 60	• 61	• 62	• 63	• 64	• 65	• 66	• 67	• 68
• Survey Monkey Question	• 25a	• 25b	• 25c	• 26	• 27	• 28	• 29	• 30	• 31	• 32a	• 32b	• 32c	• 33

### Appendix 3.2 Standardisation of sexual function values

EPIC Item	Survey monkey question	Response	Standardised Value	Excel spreadsheet code for standardisation
56,57,58,60,61,62,63,64	25a,25b,25c, 27,28,29,30,31	1,2,3,4,5	0,25,50,75,100	<p>=IF(AND(BV3=1),"0",IF(AND(BV3=2),"25",IF(AND(BV3=3),"50",IF(AND(BV3=4),"75",IF(AND(BV3=5),"100")))))</p> <p>Q25a Initial excel cell =BV3</p> <p>Q25b=BW3, Q25c=BX3, Q27=BZ3 , Q28=CA3, Q29=CB3 Q30=CC3, Q31=CD3</p>
59	26	1,2,3,4	0,33,67,100	<p>=IF(AND(BY3=1),"0",IF(AND(BY3=2),"33",IF(AND(BY3=3),"67",IF(AND(BY3=4),"100")))))</p>
65,66,67	32a,32b,32c	0,1,2,3,4	100,75,50,25,0	<p>=IF(AND(CE3=0),"100",IF(AND(CE3=1),"75",IF(AND(CE3=2),"50",IF(AND(CE3=3),"25",IF(AND(CE3=4),"0")))))</p> <p>Q32a Initial excel cell= CE3</p> <p>Q32b=CF3 , Q32c =CG3</p>
68	33	1,2,3,4,5	100,75,50,25,0	<p>=IF(AND(CH3=1),"100",IF(AND(CH3=2),"75",IF(AND(CH3=3),"50",IF(AND(CH3=4),"25",IF(AND(CH3=5),"0")))))</p>

(Maximum standardization value for sexual function=100)


### Appendix 3.3: Matching urinary function survey monkey questions to EPIC scale

	Urinary Function											
Epic Item	23	24	25	26	27	28	29	30	31	32	33	34
Survey Monkey Question	34	35	36	37	38	39a	39b	39c	39d	39e	39f	40

### Appendix 3.4 Standardisation of urinary function values

EPIC Item	Survey monkey question	Response	Standardised Value	Excel spreadsheet code for standardisation
23,24,25	34,35,36	1,2,3,4,5	0,25,50,75,100	=IF(AND(CI3=1),"0",IF(AND(CI3=2),"25",IF(AND(CI3=3),"50",IF(AND(CI3=4),"75",IF(AND(CI3=5),"100"))))))  Q34, Initial excel cell= CI3,  Q35= CJ3, Q36= CK3
26	37	1,2,3,4	0,33,67,100	=IF(AND(CL3=1),"0",IF(AND(CL3=2),"33",IF(AND(CL3=3),"67",IF(AND(CL3=4),"100")))))
28 to 33	39a to 39f	0,1,2,3,4	100,75,50,25,0	=IF(AND(CN3=0),"100",IF(AND(CN3=1),"75",IF(AND(CN3=2),"50",IF(AND(CN3=3),"25",IF(AND(CN3=4),"0"))))))  Q39a, Initial excel cell=CN3,  Q39b =CO3, Q39c =CP3, Q39d =CQ3, Q39e =CR3, Q39f =CS3
34	40	1,2,3,4,5	100,75,50,25,0	=IF(AND(CT3=1),"100",IF(AND(CT3=2),"75",IF(AND(CT3=3),"50",IF(AND(CT3=4),"25",IF(AND(CT3=5),"0"))))))

**A systematic review has found  
that little evidence exists, none of  
it high-level, concerning the  
impact of prostate cancer on the  
quality of life of gay men.**






**[goo.gl/2S2Kk](https://goo.gl/2S2Kk)**

**The quality of life of gay men diagnosed with prostate cancer:  
a systematic review**

C. Thomas<sup>1</sup>, A. Wootten<sup>2</sup>, P. Robinson<sup>1</sup>

1. La Trobe University, Melbourne    2. Australian Prostate Cancer Research Centre, Epworth





## Appendix 4.2 Poster presented as part of the PhD program

# AN ONLINE FOCUS GROUP TO INVESTIGATE THE EXPERIENCES OF GAY AND BISEXUAL MEN DIAGNOSED WITH PROSTATE CANCER.

### AIM

Aim: To investigate the experiences of gay and bisexual men diagnosed with prostate cancer.

### METHOD

Method: An online focus group of nine gay men and one bisexual man was conducted over a four week period with participants responding to a range of discussion questions concerning their experiences following a prostate cancer diagnosis.

### RESULTS

Results: All men who took part in the online focus group reported that prostate cancer significantly impacted their lives.



### STIGMA

Incontinence curtailed social interaction, routine domestic issues and produced a sense of regret for some men.

Sexual changes impacted on gay identity and masculinity.

Aspects of life were re-evaluated to assess their importance.

Sexual relationships were changed.

### SUPPORT

Help and support came from family and friends rather than from a partner.

Emotional responses to a diagnosis of prostate cancer included shock, disbelief and the need to confront one's own mortality.

Warmth and sincerity were seen as desirable traits in the treating urologist.

A structured care and support plan was considered to be essential for improved quality of care.

### CONCLUSION

Conclusion: Specialised supportive care is required to overcome the burden of stigma felt by gay men diagnosed with prostate cancer.

Authors: Christopher Thomas<sup>1</sup>, Aodie Wooten<sup>1</sup>, Priscilla Robinson<sup>2</sup>  
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Image based on the work 'Follow your dreams' by Denzly

