

Sexual Issues in Partners of Cancer Patients

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Sexuality and Cancer

- Focus on person with cancer – sexual functioning
- Sexual and reproductive cancers
- Heteronormative framework
- Need to acknowledge:
 - Sexual needs and concerns of the partner
 - Negotiation of sexual changes in the context of the relationship
 - Across tumour types
 - Sexuality and gender diversity



Gendered experiences of Cancer Care ARC Linkage Grant

Jane Ussher, Phyllis Butow
Western Sydney University, Sydney University

In partnership with
Gillian Batt, Gerard Wain, Laura Kirsten, Kim Hobbs, Kendra
Sundquist,

Cancer Council NSW, National Breast Cancer Foundation, Westmead Hospital & Sydney West Cancer Network Psycho-oncology Service,
Nepean Hospital - Cancer Care Centre,



Australian Government
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Sexuality and partners

- *Survey:* 156 partners - 55 men, 101 women
- *Interview:* 20 partners - 11 men, 13 women

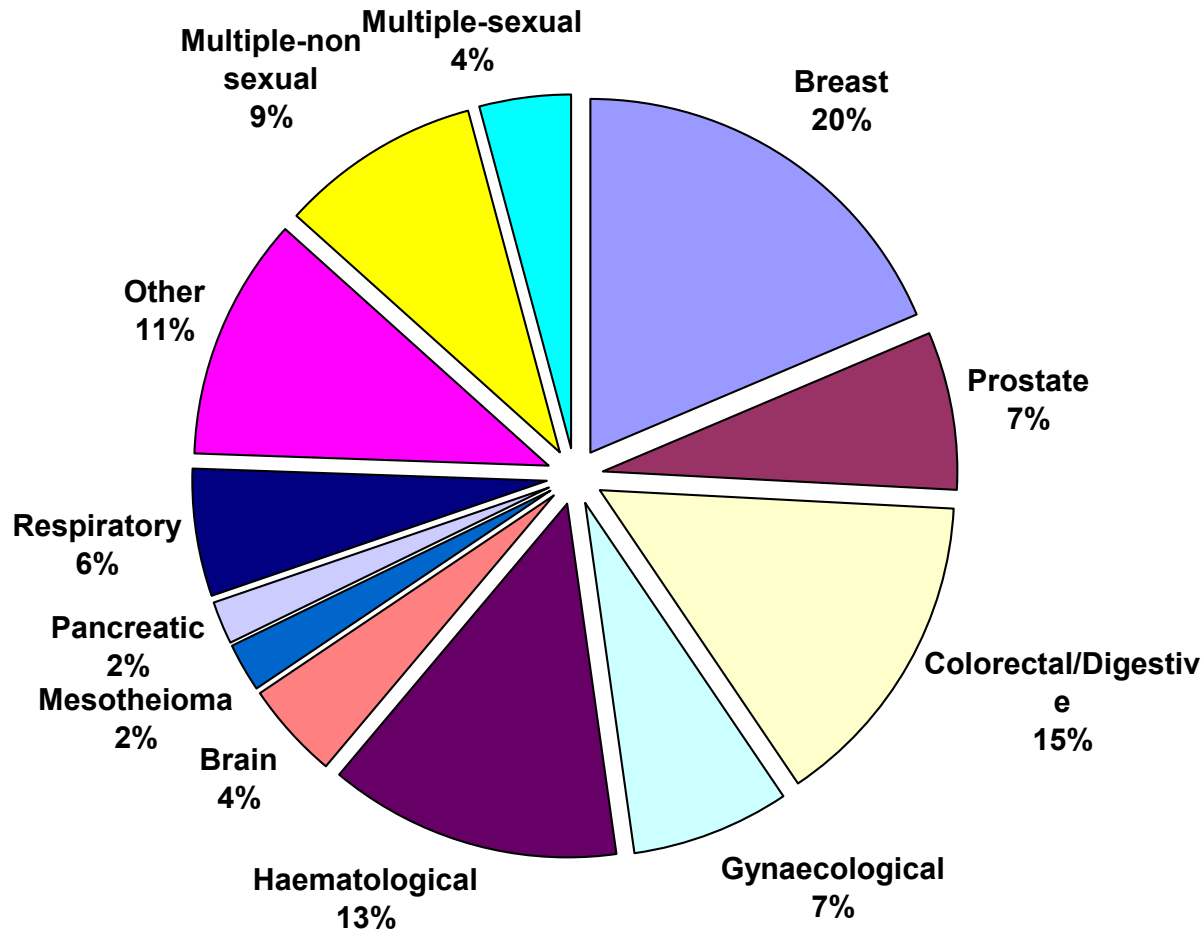
91% heterosexual; average age 56

- 122 (78%) - cancer negatively impacted upon their sexuality and their sexual relationship
- Overall impact:
 - 76% 'non-reproductive' sites
 - 84% 'reproductive' sites

Sexuality and Partners



Australian Government
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The construction and experience of sexuality in the context of cancer: Patient, partner and health professional perspectives

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ARC Linkage Grant

In partnership with

Gillian Batt, Annie Miller, Alison Butt, Pandora Patterson, Gerard Wain, Cathy Mason, Laura Kirsten, Kim Hobbs, Kendra Sundquist,

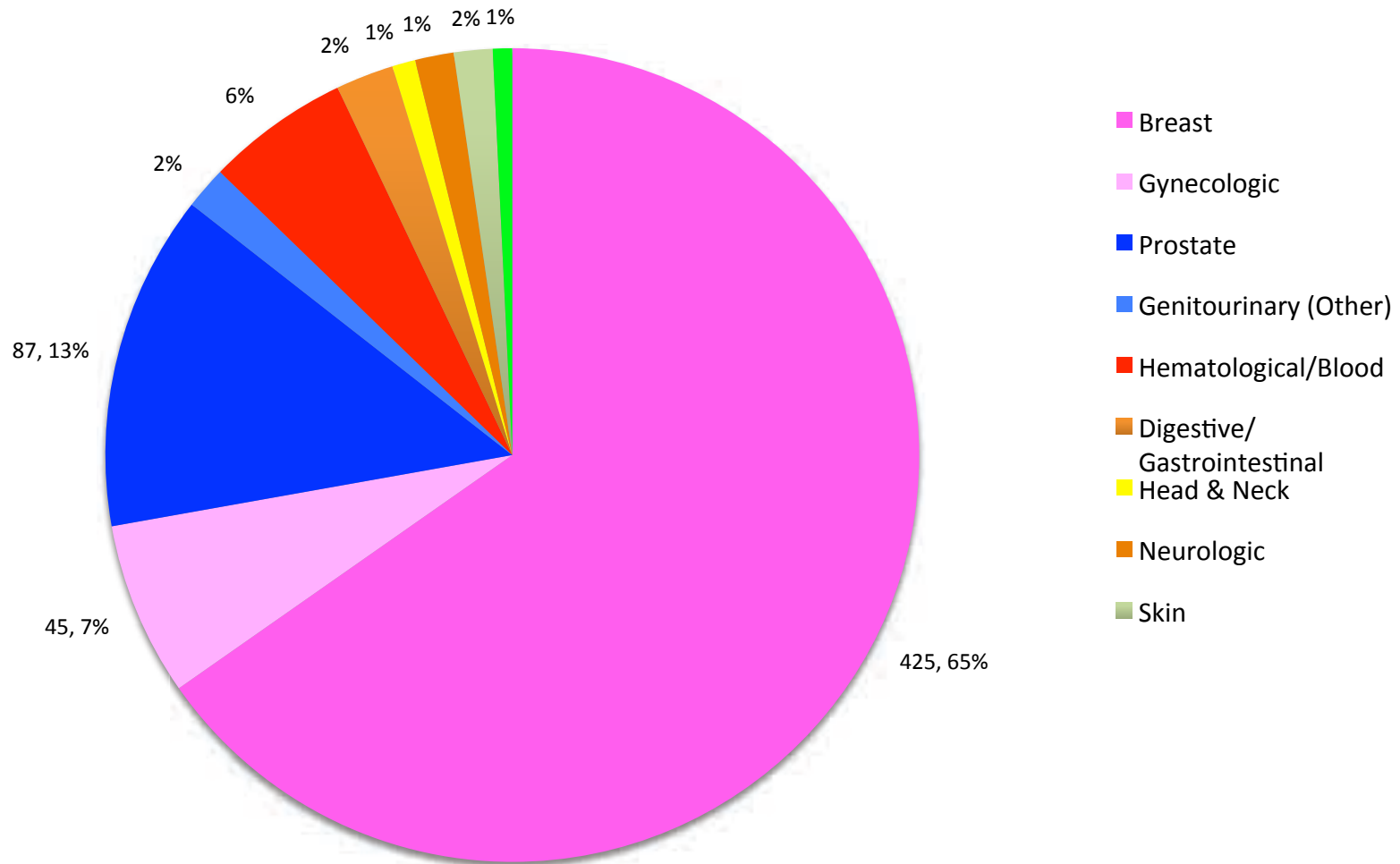
Cancer Council NSW, National Breast Cancer Foundation, Westmead Hospital & Sydney West Cancer Network Psycho-oncology Service, Nepean Hospital - Cancer Care Centre,

Participants

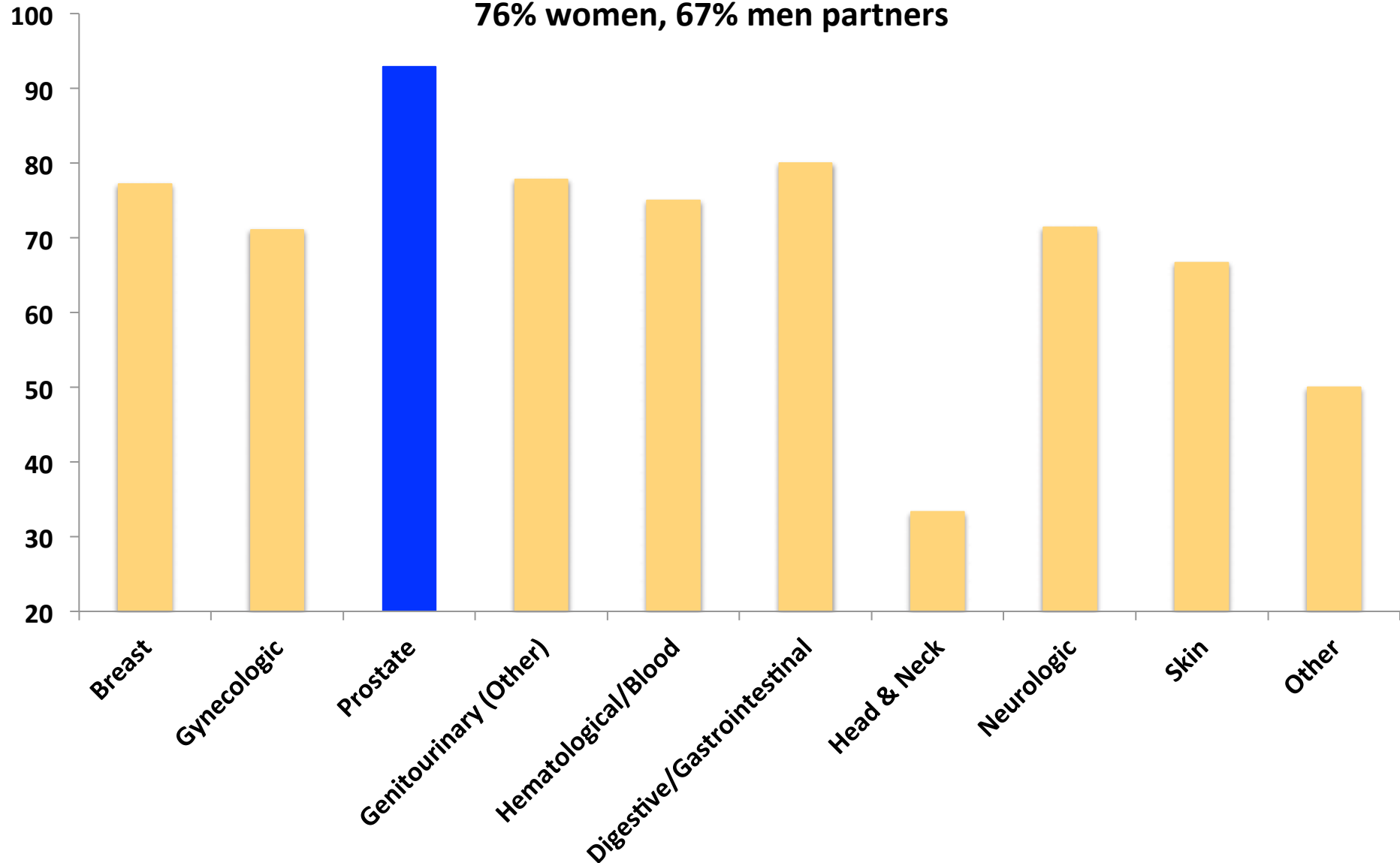
Survey: 942 People with cancer (PWC).
193 partners (87 women, 61 men);

Average age 56
91% Heterosexual

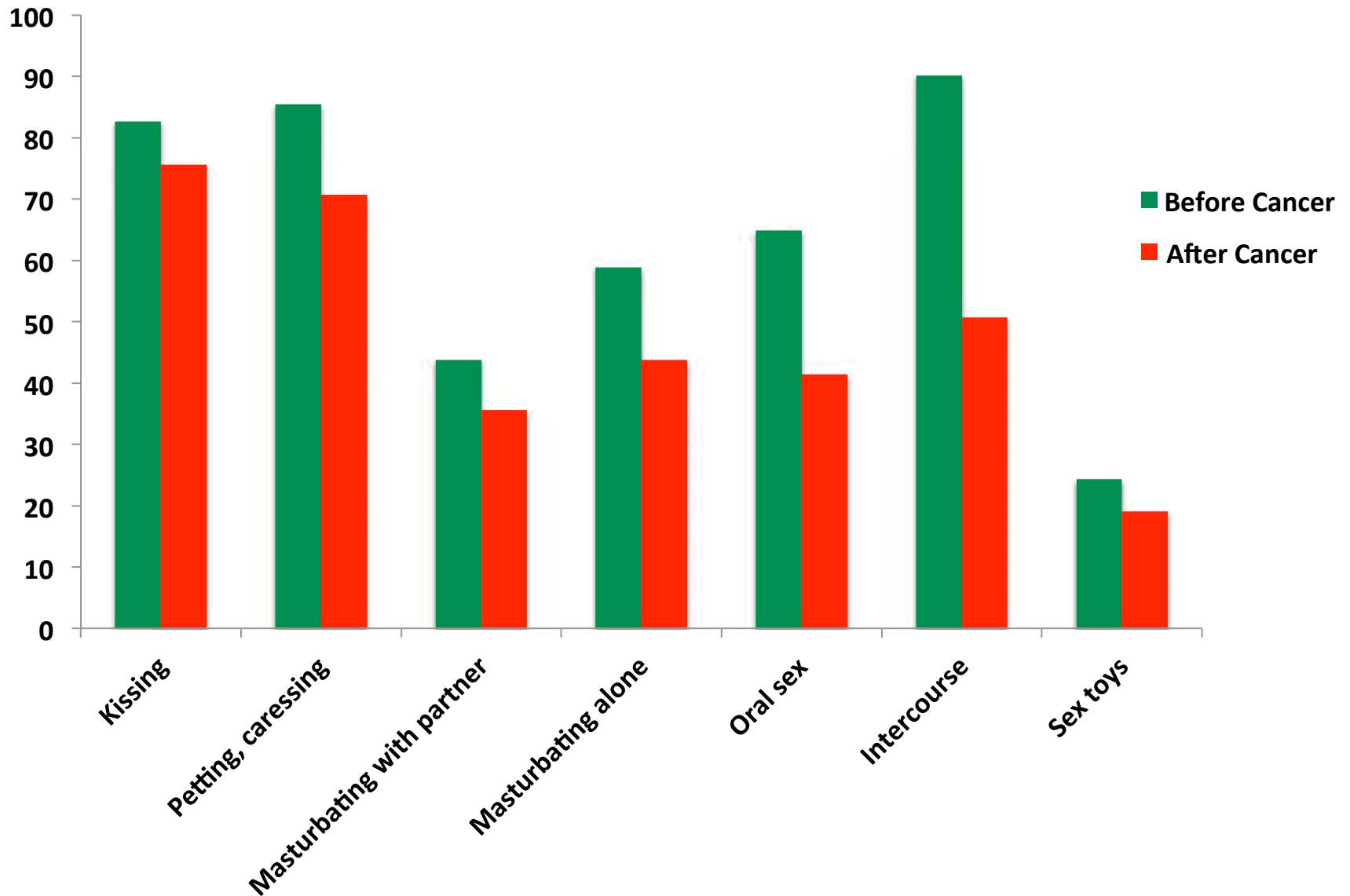
Interviews: 44 PWC; 39 partners



Have your sexual activities changed since the onset of cancer? 76% women, 67% men partners



Types of sexual activities



Perz, J., Ussher, JM., & Gilbert, E. (2014) Feeling well and talking about sex: Psycho-social predictors of sexual functioning after cancer. *BMC Cancer* 14:228-247. DOI:10.1186/1471-2407-14-228

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

CIs: Jane Ussher, Janette Perz, Suzanne Chambers, David Latini

Als: Gary Dowsett, Ian Davis, Scott Williams, Ian Brotherton

Research Officers: Duncan Rose, Andrew Kellett

Collaboration: University of Western Sydney, ANZUP, Griffith University, La Trobe University, Baylor College, ACON

Funding Prostate Cancer Foundation Australia (PCFA)

Experience of Gay/Bisexual Men with Prostate Cancer

Gay/Bisexual Men (81% Gay, 19% bi)

- N= 124 (survey); 46 (interview)
- Average Age = 64

Partners

N= 47 (survey); 9 interview

- Average Age = 62

Comparison Group: Heterosexual men

- N= 225 (survey); 44 (interview)

All men reported sexual changes

GB Men

Significantly Higher:

- Sexual functioning
- Cancer related distress

Significantly lower:

- Health Related Quality of Life
- Psychological Wellbeing
- Masculine Self Esteem

Confirms Hart et al 2014 (89 Ss); Torbit et al 2014 (92 Ss) – both studies comparison with population norms

Ussher, JM, Perz, J., Kellett, A., Chambers, S. Latini, S., Davis, S., Rose, D., Dowsett, G., Williams, S. (2016) Health Related Quality of Life, Psychological Distress and Sexual Changes following Prostate Cancer: A comparison of Gay and Bisexual men with Heterosexual men. *Journal of Sexual Medicine* 13, 425-434 doi.org/10.1016/j.jsxm.2015.12.026



Sexual *dys*-embodiment

The body and self experienced as
dys-functional, ill, and at odds with one's
desired presentation of the self

(Kelly & Field, 1996).

Patient's Loss of Desire

*As a **result of treatment** (chemotherapy) my wife is tired more of the time and **her libido is reduced***

*

the initial wish is not there you see.
You don't really want to, it's just like
you have no desire to be sexual
Alf, age 57, hetero

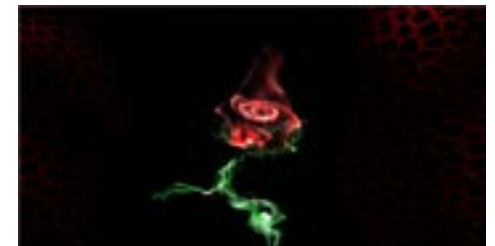
radiotherapy resulted in 'the end of an active physical, sexual life. **I've lost the urge to have sex**, I've lost the ability to have decent orgasms'
Stuart, age 60, gay

Ussher, JM, Perz, J & Gilbert, E. (2015) Perceived causes and consequences of sexual changes after cancer for women and men: a mixed method study. *BMC Cancer* **15**:268, 2-18 doi: 10.1186/s12885-015-1243-8

The biggest effect is the instant menopause which means **loss of passion**

Ursula, 47, ovarian, hetero

I even shelved my own sexual needs so I was fully and utterly 100% celibate. It just didn't, it just got stopped, **my sexuality just stopped** (...) my sexuality was shelved, shelved but it was still there
Andrea, 36, melanoma, lesbian.



Patient's body image concerns

Due to the lack of body parts ***I feel less like a sexual being and more like a breathing blob.*** That contributes to the fact that I have no inclination to have sex
Helen, 48, gynecologic, hetero

My body is grotesque so I do not want anyone to see or touch me
Ann, 50, breast, hetero



Even when I am drawn to someone, I wouldn't go there, because ***I feel so sexually unattractive*** that I think, no, I wouldn't do that to you
Bronwyn, 50, breast, lesbian

I felt bloody terrible, because I've always had a fairly decent dick... and ***a couple of our friends have got small dicks***, so I thought, I've always thought, "you poor bastards", and ***now I'm in the same boat as them.***

Scott, 59, gay

you lose drive, you put on body fat, you lose muscle tone. Sexually you're finished

David, 69, prostate, hetero

Partner avoiding sex – avoiding distress

with erectile dysfunction, I think it hits their core, their manhood core (...) he was sexually active, very active, and ***he sort of felt he lost his manhood***

Shirley, age 68, early prostate, partner

I wouldn't be being a good wife to him if I was demanding anything of him that he couldn't follow through with and I wouldn't be fair on him if I was pressuring him. I'll be very honest, but ***it wouldn't be fair on him to make him feel even worse than he does*** to say well, “why can't it be like before?”, ‘cause reality is it won't be at the moment.

Jenny, 29, recurrent brain tumour, partner, hetero



Fear of causing pain

It puts a damper on the free flow because part of your brain is always [thinking], we've got a port-a-cath, I can't go near her on this side and ***we've got a sore and sensitive area so you can't sort of suddenly give her a big cuddle.***

Ed, age 54, breast, partner, hetero

*I'm not talking to her about it, because I don't want to **put that stress on her, or hurt her***

Sean, 64, breast, partner, hetero

Feeling guilty about sexual desire

I should be able to just deal with it, you know, just ***stop acting like an animal because 'she's a sick woman'***.

I hate the idea of basically skulking away in the office and going to bigtits.com or whatever and just jerking off, it sort of makes me feel like I'm just a grotty 16 year old again, ***I should just be over it.***

Paul, 45, breast, partner, hetero

Gilbert, E., Ussher, J.M., & Hawkins Y. (2009). Accounts of disruptions to sexuality following cancer from the perspective of informal carers who are partners of a person with cancer. *Health: An Interdisciplinary Journal* 13 (5) 523-541

Sexual Frustration

It's more frustration than anything, especially if we start to be intimate and he can't, that upset him. At first ***I would just walk out of the room and just get furious because I still wanted it.***

Jenny, 29, brain tumour, partner, hetero

I just think ***why get yourself all stimulated if you can't do anything anyway***

Melanie, 52, prostate, partner, hetero

Sexual Disinterest

Positioning partner as a child, or asexual 'sick' patient

You've lost the relationship that you had, and ***the relationship is redefined***. So, where it was a sharing intimate relationship, ***it's now what you would do with your children***

Sarah, 57, partner, hetero

They're not the person that they were (...) they're now this person that you care for (...) it feels as if we're just sharing a life and that it could be my brother or whatever, because ***I don't have any physical attraction towards him whatsoever.***

Melanie, 52, prostate, partner, hetero

Sexual Disinterest

Worry and tiredness

I wasn't even thinking about, you know, *doing the business* during that whole initial sort of period

Ted, 57, colorectal, partner, hetero

My sexual desire had diminished *in the beginning* [pause] because you know *you're concerned and you're not interested in sex*'.

Jessie, 36, breast, partner, lesbian

I became just too tired to be very interested in sex. I would often just fall asleep and didn't really compensate in any sort of personal private sense, you know, masturbation'

Margaret, 71, bowel, lung and liver cancer partner, hetero

Emotional consequences of sexual changes

*It distresses me greatly, my partner displays his emotions readily, even now still **would breakdown and cry** when he was thinking about, you know, **what he's lost sexually**. And that - that's very – that's **very hard for me to watch him go through**, and, I guess, it's also – it becomes very – **very tiring**.*

Terry, 53, prostate, partner, gay

Sadness

It's profound sadness, I mean very, very sad'. I feel ***terribly fragile and vulnerable and sad***, and so sorry that it was all going'.

Diana, 44, prostate, partner, hetero

For me the reality was starting to set in of ***the sadness that I wouldn't be able to procreate*** with him in that very natural, very intimate environment which most couples take for granted.

Bella, 36, prostate, partner, hetero

Resigned

I think for me, I just sort of felt, well ***we've had good times, we've had a good sex life, be grateful for what you've had*** (...) I feel that I resigned myself to the fact that this was how it was' .

Maxine, 67, prostate, bowel, lung, and brain cancer partner, hetero

I'm a bit disappointed that we no longer share a sexual relationship, but ***I don't dwell on it too much because it's part of life.***

Bob, 69, breast, partner, hetero

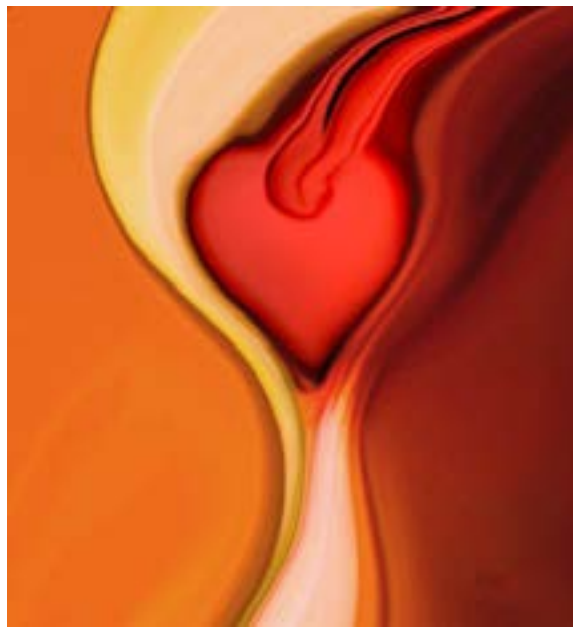
Accepting sexual changes

Oh well, there's no erection. ***I don't think every woman would put so much emphasis on it as the males do.*** It's just the B-all and end all, and when it's not there it's, they're just so crushed and they don't feel as if they're a man anymore, and oh my God, their life's, it's just not worth living anymore if they can't do it.

Angie, 52, prostate, partner, hetero

Gender Difference in importance of sex - carers study

	Women partners		Men partners	
	n	%	n	%
Sex important part of the relationship:				
Very important	24	31.6	27	50.9
Somewhat important	41	53.9	22	41.5
Not important	11	14.5	4	7.5
Sex important part of life:				
Very important	20	23.5	29	47.5
Somewhat important	52	61.2	27	44.3
Not important	13	15.3	5	8.2



Sexual re-embodiment and re-negotiation

narrative reconstruction, coping and
adjustment, which results in a realignment
of body and self

Women re-embodiment sexual subjectivity - partner support

I was always too heavy, too wobbly, and not big enough in my boobs, legs too short. I was always far more critical of my body than I am now.

My husband always tells me I'm beautiful

Heather, 49, breast, hetero



After the surgery ***I had my full back tattooed with butterflies and roses. My partner*** sees my tattoo and she ***absolutely loves it***, she doesn't see the scar.

Vicky, 36, pwc, melanoma, lesbian

Despite having a big hole and a big scar in one breast, the intimacy is greater than it was before, and ***I still feel very sexy.***

Nina, 48, breast, polysexual

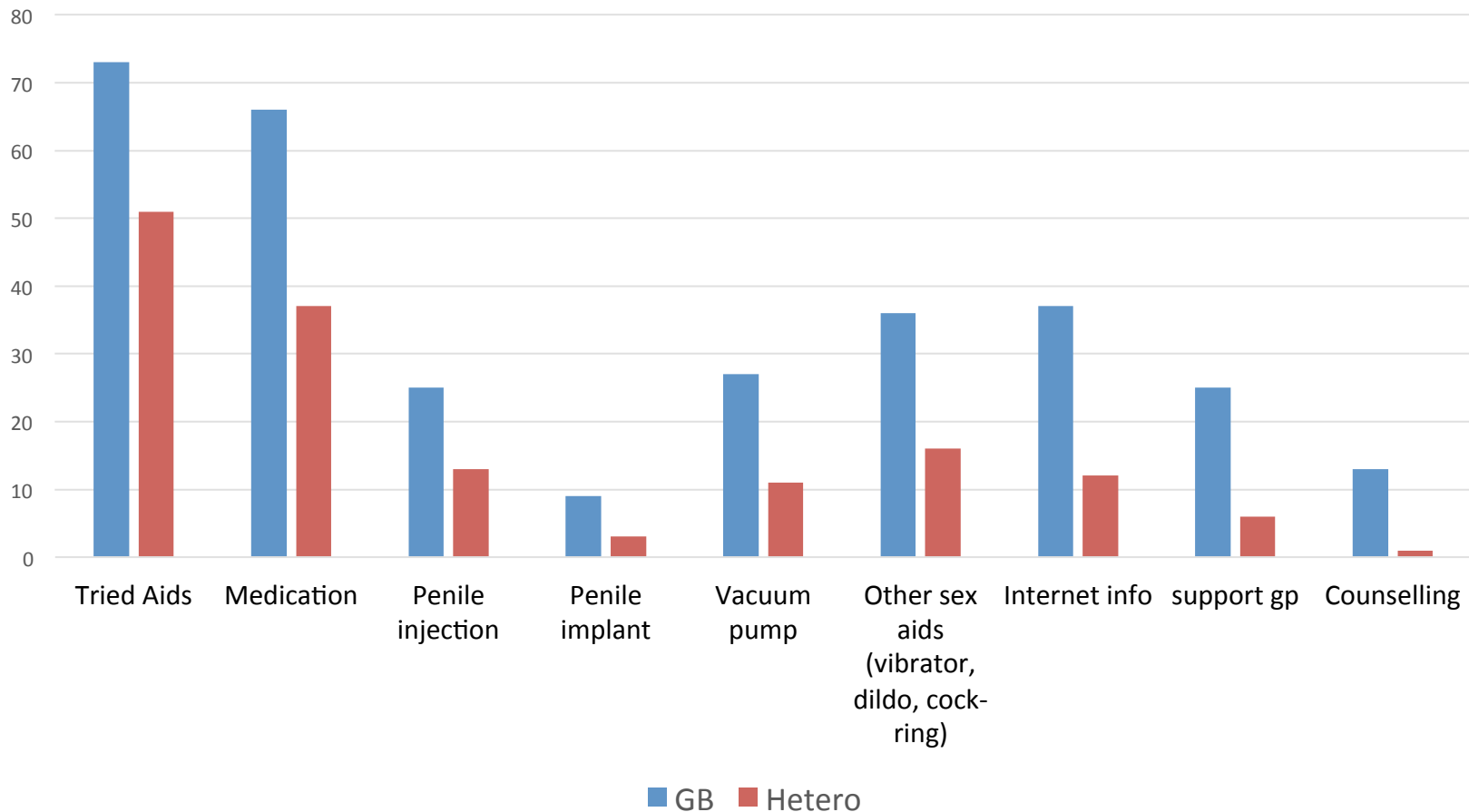
Men re-embodiment sexual subjectivity

- Viagra, penile injections, pumps and implants

Charlotte (66, partner) described her husband's penile implant as “*a God send for him,*” which made their relationship “a lot stronger, because you're not, sort of falling apart because you can't have sex anymore.”



Gay and Bisexual Men: Greater Use of Assistive Aids and Sexual Information



Ussher, J.M, Perz, J., Rose, D., Kellett, A., Dowsett, G. (2018) Sexual Rehabilitation after prostate cancer through assistive aids: A comparison of gay/bisexual and heterosexual men. *Journal of Sex Research* DOI: 0.1080/00224499.2018.1476444

Sexual renegotiation: *Re-Defining 'sex'*



I deeply ***reject the idea that sex is all defined in terms of the cock and what it does***, where sex starts when the guy gets an erection and ends when he's had an orgasm and that's it.

Nina, 48, breast, poly-sexual

a couple can have a really strong relationship, an intimate physical one, ***without straight sex***, like penetrative sex

Debbie, 71, prostate, partner, hetero

sex is not just penetration

Clinton, 57, leukaemia, partner, hetero

Ussher, JM, Perz, J. Gilbert, E., Wong, WT, Hobbs, K. (2013) Renegotiating sex and intimacy after cancer: Resisting the coital imperative. *Cancer Nursing* 36:6 454-462

Exploration of non-coital sexual practices

We were like, oh, ***two puppies playing together***, even though I'm 59 and he's 74. Um, and even sort of simulated sex we'd get on top of each other and not actually have sex but, you know, sort of ***loving each other in a sex position***

Nelly, 59, lymphoma, partner, hetero

my doctor told me ***I was engaging in outercourse not intercourse***, which almost gave it a clinical term that made me happier.

Colin, 65, prostate, partner, gay

Good sex - Better sex

Learning different techniques on how to do hand jobs and, and just things like that is interesting and fun, and **our sex life is very good.**

Ruby, age 49, prostate partner, hetero

One of the things about BDSM is that there's like 500 things on the list to do, one of which is sexual intercourse. So **there's lots of other options.**

Nina, 49, breast, polysexual



Our sexual relationship has **probably got better** since my wife got sick, because **we spend a bit more time in foreplay**, to sidestep the vaginal dryness.

Henk, 63, partner, breast, hetero

If you'd said to me prior to the operation that you would have felt **the intensity of love and lovemaking that you felt in the first year**, you know, new love and all that sort of stuff, I would have said you are bonkers, but **that's exactly what's happened to us.**

Terry, 53, prostate partner, gay

Renegotiating Sex: *Embracing intimacy*

Well, I guess we sleep together, so that's a good thing [chuckles], and ***cuddle up, and touch, and that sort of thing is always good.***

Henna, 59, colorectal, partner, hetero

We hug a lot and we um, in bed, ***I would cuddle up*** as much as I can, [Pause] when he comes home, ***he always kisses me hello*** and so on. he'd just ***stop me in the kitchen and put his arms around me.*** He hasn't had an erection for nearly 12 weeks, and it's impossible for him to get one. So ***that little aspect of intimacy is very important to me.***

Gerald, 65, prostate, partner, gay

Intimacy = closer as a couple

being really very close together

Charlotte, 66, prostate, partner, hetero

being “part of one another”

Pearl, 64, prostate, partner, hetero

we’ re closer than before the cancer, when it was
more sexual, like more lust

Russell, 39, breast, partner, hetero

Couple Communication: Predictor of sexual functioning after cancer

- ‘We discussed it a lot’
- ‘if there was a need for something else (sexually) then one or the other would say so’ .
- ‘we always promised to always have really good communication before this happened and we both really made an effort to keep that going’

Perz, J., Ussher, JM., & Gilbert, E. (2014) Feeling well and talking about sex: Psycho-social predictors of sexual functioning after cancer. *BMC Cancer* 14:228-247. DOI:10.1186/1471-2407-14-228

Communicating about sexuality with health professionals

Facilitates couple communication



Cancer partners

Hawkins, Y., Ussher, J.M., Gilbert, E., Perz, J., & Sandoval, M., Sundquist, K. (2009). Changes in sexuality and intimacy following the diagnosis and treatment of cancer: the experience of informal cancer carers. *Cancer Nursing: An International Journal for Cancer Care* 34 (4), 271-280

- 20% had discussed changes to sexuality with a health professional
- 37% (of 20%) indicated that they were 'satisfied' or 'very satisfied' with the discussion

Cancer type	Sexuality discussed by health professional
Prostate	50%
Breast	30%
Respiratory cancer	0%
Brain	33%
Pancreatic	33%
Gynaecological	29%
Multiple – sexual	21%
Colorectal/digestive	17%
Mesothelioma	17%
Multiple – non sexual	15%
Other	15%
Haematological	9%

Sexual communication after cancer

Survey 942 people with cancer; 193 partners

Discussion of sexuality with HPs:

People with cancer: 43% women; 67% men

Partners: 47% women; 28% men

Sexual cancers 50%; **non sexual cancers** 68%

Greater focus on men with cancer, and on sexual cancers

Gilbert, E., Perz, J. & Ussher, JM. (2016) Talking about Sex with Health Professionals: The Experience of People with Cancer and their Partners. *European Journal of Cancer Care* 25, 280-293 doi: 10.1111/ecc.12165

Sexual dysfunction was never mentioned as a side effect of cancer treatment and yet it is the one side effect that has had a long term impact on our quality of my life.

Oliver, 42, ovarian, partner, hetero

We were never informed about possible negative side-effects such as not being able to experience penetration.... as we had done for 8 years prior to diagnosis, surgery and treatment. I have always thought this problem was mine alone – no one had ever talked about it including other patients, doctors etc. **I now know that this situation happens to many couples. If so then we should have been forewarned.** No wonder so many marriages fail when both are affected by the treatment consequences.

Jen, 64, breast, partner, hetero

Heteronormativity

I think the specialist was um, he was a conservative medico, and ***I don't think he was particularly comfortable with our lifestyle....***It was all very, it was all quite cold and clinical and ***no real questioning or trying to understand our position as a gay couple.*** There were a few things thrown in about men with partners but I got the impression that he was very, ***very strongly talking about female partners,*** and, you know, the husband and wife scenario and the family scenario, but that didn't apply to us, *Scott, 59, prostate, partner, gay*

Rose, D., Ussher, JM, Perz, J. (2017) Let's Talk About Gay Sex: Gay and Bisexual Men's Sexual Communication with Healthcare Professionals after Prostate Cancer. *European Journal of Cancer Care* 26 e12469 DOI: 10.1111/ecc.12469



Conclusions

- Experience of sexual embodiment as functional, intact, and ‘normal’ , can move to a state of ‘*dys*-embodiment’ after cancer – for partners and people with cancer
- This can be followed by re-embodiment, or oscillation between the two positions

Intersection of gender and sexual identities influences this trajectory

Many Gaps.....



Out with Cancer

LGBTI experiences of cancer survivorship and care

CIs: Jane Ussher, Janette Perz, Martha Hickey, Suzanne Chambers, Gary Dowsett, Ian Davis, Kerry Robinson, Chloe Parton, PIs: Antoinette Anazodo, Fiona MacDonald

Funding: Australian Research Council Linkage Grant, 2018-2021

