

THE CHALLENGE OF PINK: SUBVERTING THE CURRENT BREAST CANCER AWARENESS PARADIGM THROUGH VISUAL AND ORAL STORYTELLING

A Thesis submitted by

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APPENDICES

Appendix A: Artist audit not included in exegesis

Artists who were reviewed in Artist Audit but not included in this exegesis.

Aboriginal Breast Screening Shawl Trial, Breast Screen Victoria in collaboration with Indigenous artists: Jemma Bamblett, Jasmine-Skye Marings, Rebecca Atkinson, Rebecca Clayton, Marilyn Fenton, Belinda Farnham, Bronwyn Ferguson, Shylee Corrigan, Trina Dalton-Oogies; Victoria Aboriginal Community Controlled Health Organisation (VACCHO) and the Victorian Aboriginal Health Service (VAHS)

Kathy Ackers (American writer)

Mania Akbari (Iranian filmmaker, artist, writer and actress)

Karike Ashworth (Australian installation artist)

Michael Armstrong (Australian photographer)

Elissa (Lebanese singer)

Martha A. Hall (American artist books)

Kate Just (Australian textile artist)

Knitted Knockers < knittedknockersaustralia.com >

Lisa McDermid (Australian photographer)

Seema Mathew (Indian painter)

Veronica Mehta (Bollywood artist, singer and songwriter)

Julie Hillocks Shinners (Australian writer)

Sam Taylor Wood (British photographer)

Appendix B1: Rod Ritchie Interview 11/9/2015

11 Sept 2015.

Rod Ritchie, 2015

and I wasn't really aware of the genetic possibilities running through the male line but I wasn't really expecting to have breast cancer. Well once you are diagnosed you really get put into a system and go through a process it's often called a journey but I call it a process because there's a lot of health professionals dealing with different aspects of the care of breast cancer patients So I was sent first of all to see the surgeon because the normal way of dealing with breast cancer surgery to cut out the cancer and then you go on chemotherapy to mop up and then perhaps radiation. In my case the breast surgeon took about 10 seconds I reckon looking at my left breast which was very inflamed, nipple was inverted and she said you have to start the chemotherapy first so you have to see the oncologist so two days later I was seeing an oncologist and she said we will start chemo first because the surgeon won't be able to cut out that material and so next Thursday from that previous Friday I started chemotherapy I was expecting worse cause you do get on the internet to see what Dr Google says about everything and I think the reaction from the chemotherapy and the physiology between males and females as well I was quite unaffected And after chemotherapy there was a chance for the surgeon then because the chemotherapy shrunk the tumours back to their original size. She could see now that it was ok to operate and she knew what she was dealing with. From the ultrasound she knew there was some lymph node involvement and she said I will probably take your lymph nodes out as well. I said what will it be, she said under your arm both lymph nodes and that there's two of those affected with cancer and I'll take them out, when I said how many she said see that shelf there everything all the way down so I was pretty clear that she wasn't selecting lymph nodes she was removing all of them. And having seen male breast tissue there and the nipple will all be removed. You will have some quite impressive looking scars and drains and in my case a seroma developed which took a bit longer to heal because remember you

are waiting to start radiation after breast surgery and they want to make sure the chest is quite flat

Well mind you it was something that I did know of because my mum got breast cancer when she was 40

before they can do that. Radiation has to be planned so another week after that I started 25 treatments one each day for 5 weeks. I survived 25 and that wasn't probably the best treatment of all so really just went and set yourself up in position and they tattooed your chest to make reference points for the radiation machine which revolved around you and whirred away probably in about 5 minutes then you are up then in about 10 minutes you were out the door and then you came back the next day to do it again. And now I am on the drug Tamoxifen which is the best drug for my kind of breast cancer which was estrogen positive and HER2 negative so that is a 5 year course. It was interesting when I asked about the side effects one thing I'll tell you is never come into breast cancer treatment with preconceived notions I thought this is good advice from this I was able to ignore the potential symptoms which included impotence, which included a lot of headaches, hot flushes things that are normal with SRM which men can get I since found out. Men who are treated for breast cancer, I have probably got a 70% chance of still being around in 5 years which I think is not too bad as I will be 65 tomorrow. That's a good question it affects everyone in my case it's made me realise that there are things I still want to do and I should do them and I think everyone needs to be realistic and get their affairs in order and that doesn't just mean paperwork, I mean I had the idea to clean out the shed that being a metaphor to clean out a lot of stuff out of your life and made me realise that also that each day handle as it comes and keep yourself healthy also make sure that you don't that you get as much exercise as you can, a proper diet, doing things that before the cancer I wouldn't have been so keen on doing. The main challenge I think is the idea that potentially you've got a disease that you thought women got but once you realise that men have got breasts as well and that there's plenty of reasons why men can get breast cancer perhaps primarily genetic reasons and Knowing that my mum died of breast cancer I thought well perhaps it's come down to me and I should make sure I let my daughters know and my nieces but also my brothers because if they have a propensity to the gene then they have a % chance of having gene problems so I guess.

And is there anything you would like to add and anything you would like to share with people that might help?

Well what I usually say to people when I speak about male breast cancer is don't ignore a lump on either side of your chest or under your arm If you don't know what to look for ask advice from a friend, your daughters anyone that's checking themselves they will tell you what to do and go to your GP for further treatment so I guess that's the main message.

About 9:00

I suppose the branding of breast cancer is that men are not aware of it, when they get diagnosed it is

usually at a later stage, and their survival rates are lower and I think what we are really doing is branding

it as a women's disease and sentencing some men to get a lesser chance of a cure from treatment.

9:41

For you it seemed like it was the radiation and losing your chest hair which was more

That's right I'm quite prone to showing my scar to anyone who wants to see it and I think cause your kids ask you if you are going to the beach and they ask you can't pretend nothing's happened I've got a friend who had male breast cancer and he tells the kids he was in a sword fight "Oh that's cool". Yeah well that's right I lost my hair, but I didn't have a lot to start with but you lose every bit of hair, but you lose every bit of hair, from the top your head to your toes and look like an android there for a while and then then your hair grows back it quite thicker and curlier depends how much and where it is. I lost my face hair as well public hair but everything seems to come back except as you said my bit of chest hair which is 50% but that's It's such minor consequence

Appendix B2: Rod Ritchie Interview 12/11/2019

27 NOV 219.

Rod Ritchie 2019

I often get asked: What is it like being a man with breast cancer? And I have to think about it because it just seems like it's such a woman's disease and I should feel a bit weird, but funnily enough I feel quite comfortable and I don't know if it because my mum had breast cancer I was half expecting to get it. I think I am willing to be a role model for men with breast cancer its ok we've got breasts we can get breast cancer so what's so difficult about that. So basically when I get to think about the obstacles that are put in front of men starting with the diagnosis can be traumatic it is always a shock when then wasn't really any uptake from my General Practitioner about the disease about me having the disease so I over a period of three months, I went back three times, my doctor who has probably been seeing a thousand women with breast cancer didn't see me as being a breast cancer candidate. So on the third visit I talked her into sending me for a scan and then following that the rest is history. So I always start by saying to people to men stick up for your rights even if you don't have a genetic propensity to get the disease get yourself checked if you've got the symptoms get yourself properly appraised and if its treatment you need you will find it is better treated very very equally in surgery, radiation and chemo it is all just as traumatic for either sex.

You were telling me before how it took ages to get a diagnosis.

Yeah that's right. I took me three visits to my GP and I thought I know there's something wrong with me but she kept saying no there's nothing going on there but the third time I was insistent on a scan and in this case an ultrasound because they're a bit easier for men most people probably understand and sure enough the ultrasound technicians eyes popped out of her head and called in the doctor and I went oh oh this isn't good and so a biopsy followed and of course the diagnosis Now L think that's a shock obviously but for some reason I half expected that diagnosis from something I don't know maybe

think being prepped up for it was good. Treatment for it was very prompt and the surgeon started to examine taking over from the oncologist. The oncologist had chemo and that was the right way to go.

The tumour was shrunken down considerably I mean chemo's no fun but once you do it there the surgeon was happy to do the operation after that and a little while after that was radiation and for now the treatment is Tamoxifen which women know very well as a hormone blocker I've been on that for 5 years now and I don't have any evidence of the disease. But during that time I was sort of thinking why it isn't more known men get this disease.

About 2:10 second video

I keep coming across some red flags I think I was always wondering why other men I knew who had it were too embarrassed to come forward. I thought: What's the basis of this? I believe cancer charities, breast cancer charities have got a pink mindset and it's almost trivialising the disease and we're having a party every October it doesn't sit well with a lot of women I know with breast cancer and I think as far as the men goes it puts them in a frame of mind it makes them perhaps more embarrassed it makes them certainly less likely to come forward because they're not even aware of it. So what I am thinking is there's some obstacles for men and I would like the medical profession who should be very aware of this disease is not just women this disease is genderless and we don't hear people with melanomas or lung cancer as having talking about one sex getting harm it is genderless. So I think when I was thinking about the problems and apart from the pinkness of the charities I thought of there's a lot of a lot of misinformation around and I thought well we need to somehow have changes in the way that the education of the way this disease is presented. So I worked with some pink charities I think they were really quite responsive, embarrassed to think that they were actually neglecting 1% of their new diagnoses, because we are 1 in 100. I have noticed over the last few years is really big changes in the

way the disease is talked about, more inclusiveness that men are feeling. I think it really takes an important person to come out and get a lot of publicity. Just this year a well-known person by the name of Matthew Knowles probably unknown except that he happens to be Beyonce's dad. He decided, good luck to him, he decided to come out in public and on the major TV shows and was able to get to a very wide audience talking about his experiences talking about that men get this disease too and you needn't be embarrassed but you can actually get help the same way as women do. Your prognosis is pretty much the same and I think that makes a huge difference. I think in Australia we are finding that there's changes as well caught up in the stigma in the future.

When I first interviewed you it was in 2015, it is now 4 years later. What are the changes you have seen in the 4 year period?

Ok there has been a lot of changes, firstly the two major breast cancer charities Breast Cancer Network Australia and the National Breast Cancer Foundation have embraced men on part of their websites and in their publications and whereas we are not necessarily seeing men on a billboard were seeing the text is very much degendered it's people getting breast cancer or Australians getting breast cancer. So the idea is a patient is just seeing pink seeing us, women here doing, that most of the models are women for fundraising I haven't felt so isolated in that time since we started talking 4 years ago. I'm feeling we are more included and the men I talk to seem to be more open and I am really hoping that there will be more men come out and speak about their treatment and their diagnosis.

Have you got a hereditary breast cancer?

I have a BRCA I variation of unknown significance I was tested for the BRCA gene because my mum died as a younger woman aged 41 and of course back then there wasn't genetic testing to my result isn't proof that I have the gene propensity except that I have a genetic variation of the BRCA 1 gene, clinically the doctors do nothing about that but to me when I got prostate cancer two years after breast cancer in

walking round with two cancers. So I am treating myself as though I have a genetic form of the disease however I have two children who I am very keen to have be in a program where they get a call back each year or a letter to tell them to do screening. I am clear that I have that now. I have a daughter and a son Very quickly after I was diagnosed my daughter was put into a program a public health program that call them back each year for a MRI, for a physical examination and an ultrasound very good surveillance for her and she is very happy with that. My son after all his father had breast cancer, his grandmother had breast cancer has no such program, he's on his own, he's basically you know he can check himself without a scan but it seems like that's a discrimination that's really not fair.

You were saying before too that you had some obstacles, some obstacles with your diagnosis you have mentioned about the pink thing what do you think might be the stigma for some men?

Look I think the stigma is a gender hang up so while in my own case I pretty much avoided it or pretended to avoid it I got through it. I do see it cropping up and of the 150 men in Australia each year diagnosed I might meet 1 or 2 or them and I am on all the public blogs that deal with breast cancer and

9

there is a move for some breast cancer charities to be inclusive of the men now but those men are still

being diagnosed still been treated but they are not coming out.

And what do you think might have to happen to do that?

I feel they won't come out until they feel comfortable who would it is a bit like gender inequality in women it took some brave women to come forward and to be comfortable in presenting the message that women have equal rights as men and now it's the same thing it's the men who are pioneering, men with breast cancer are pioneering the whole the public message and they are actually getting through hopefully to the charities that are they will make more of an effort to include men and I think it might take a few years I mean how long did it take for suffragettes to get the vote? 10, 20 years?

11800

J.

What do you feel needs to be for men to have a sense of belonging?

We need to feel like we are part of the we are part of the cohort, we need to feel like we are going to be accepted as men with the disease and not put in a corner, whispered about we need to belong to the breast cancer community and I have tried to do that through social media particularly on twitter I've got 1300 followers most of those people are medical professionals and its taken me 4 or 5 years to get a profile and to be posting enough relevant information to feel quite included and I'm very proud of that and I am hoping that as more men come forward that they are seen in the media that there a sense of inclusiveness will be there.

In conclusion is there anything on this list and what would you like to say?

I think everything is there.

10.

You were talking before that some men would like to change the name because they think it's a stigma what's your opinion.

I've heard from several men that when they were first diagnosed that they were happy to call breast cancer chest cancer because of the before mentioned stigma the feeling that they were embarrassed to have a woman's disease but I found also that there is no movement generally anywhere to talk about chest cancer in became then very confusing and in fact while those men might have felt they were saving embarrassment they were actually making it harder to get the message out and so I nearly always like to say don't forget men have breasts too and the people say give us a break but men have breasts too its more exact and that bit of breast tissue can get the disease it can get cancerous just the same way that women's do

What can men do to help themselves like you had to ask for multiple times, my daughter asked this question how do men know that he's got breast cancer? What is something simple that he could do?

I think typically men are very loathed to come forward and the doctors know this they usually see men when they are way down the path, with a lot of diseases not just cancer. I think breast cancer is not a special case I think men can only help themselves by being educated, to be made less discriminated against if they do have the disease they need to overcome that and get themselves treated.

Now just going down to the grass roots of it, currently men even with a genetic background they are not in a screening program.

Men they are not in any screening program their doctors can send them off for a scan and if there is a family history they probably won't have to pay for that scan (is this true?) but if a men doesn't have a family history and maybe has the BRCA gene and no family history it is often harder to get approval for a scan but I believe there's a change and there is legislation that makes MRIs available for women and from what I understand that will follow onto men. I think that's the intention.

What about someone who has got no history of breast cancer is it like men can go forward and have a PSA test the doctors do that. I am not even sure how you found your cancer.



Okay so most men find their cancer by feeling a lump or having a nipple discharge obviously once the discharge is there it is a lot more serious and an inverted nipple so the three things are inverted nipple, discharge or a lump the size of a pea.

is that a routine thing you do?

No it's not really but when you felt your chest and you thought oohh what's that or when your partner's feeling your chest they say "Oh what's that?" So the next day you start investigating. I think well it's the same as when you've got anything a boil or a lump somewhere you wonder about it and it normally goes away. But when it doesn't go away and certainly a lump in the chest that doesn't go away I think that shows some red flags.

So just don't dilly dally?

Don't dilly dally get your arse down there and sort it out.



Do you feel that women or partners could be helpful in looking and helping men to check themselves?

Yes I do believe that I believe that women are very breast aware and could consider their partners and I think they should not force them to do anything other than say hey what's that lump or do you ever check yourself while there is a small percentage of diagnosis you still have to think well it is a possibility and yes I believe women play a role in this every man has a daughter or a girlfriend or a wife and quite often it's a woman who sends the man off for a scan.

Now the only other thing I wanted to talk about and it is because I have been reading about gender theory we start talking about transsexuals, intersex, homosexuals, lesbians like basically do you think it is about time to take the gender totally out of the conversation.

Yes

into a breast covering over the pectoral muscles that regardless of what your gender, sexual identity, or gender identity you need to be aware of it.



Yes there is a group of LGBT who are people who have got together to make their community aware and

I would put them in the same category as men and women that they are spoken about as genderless

that people get this disease that people get breast cancer and the sexual orientation, the gender is not OMIT.

the biggest part of it and once they can truly take it on board I think that's good times for everybody.

Yeah because we don't think of melanoma as having a gender we don't think of lung cancer of having a gender. I see what you mean that it has been promoted as a women's disease, it has kind of been stereotyped.

Yes literally been stereotyped and I think it will always be stereotyped to some extent but I think the message has to run parallel that other people, that all people get this disease.

Appendix B3: Rob Fincher Interview 14/2/2016

14 Feb 2016.

Rob Fincher, 2016

male perspective.

I think being a male and having breast cancer is quite an interesting journey to use an old clique. I think there's a feeling that somewhere along the line that we're a bit of a forgotten species. That this thing called breast cancer is really a female disease and I think that somewhere along the way there's a feeling of once you have been diagnosed and you go through the whole process like I did you know mastectomy, chemotherapy and radiotherapy that there's a feeling of a loss of masculinity. And that's really I guess that's difficult to deal with particularly when out there, there's a whole sea of pink, that you see just all the time I think that becomes a bit difficult for us to deal with. So that is probably what I would say from the

I guess the other thing is that when you look at a lot of the research the medication that sort of stuff that goes with the whole breast cancer discussion I think that naturally the numbers favour the female side and so a lot of the research and development goes into looking for solutions for them. But from a male perspective I just wonder whether there is anything out there at the moment that really is targeted for breast cancer in males. Is there something unique that we need to have taken into consideration? That really isn't been funded at the moment? I think that is probably one of the things problematic

How did you feel though when you were first diagnosed?

It was really a numb feeling like it was happening to someone else.



It all happened so quickly, I think it was like... if it wasn't for my wife I wouldn't have even self-diagnosed. As males don't have breasts and don't suffer from breast cancer is the normal thought process. It was only that my wife noticed an inverted nipple on my right hand side and suggested that I go and talk to my GP about it I went to see the GP and he didn't think it was anything other than a cyst and probably have it operated on and go and see a surgeon. And the surgeon, god bless him, said no I'm not going operate on just a cyst, get it checked out. It was only then that they found out that I had stage three ductal carcinoma. And then I was no sooner had I finished the biopsy then I was in having surgery and chemotherapy and radiotherapy it was just a blur. It felt quite surreal. It happened so quickly. It was sort of like an outer body experience, I guess, in some respects.

How has cancer affected you?

I think it's made me sit back and reassess what's important in life. The original diagnosis was in 2010 I went 4 years and I was having regular 6 monthly check-ups with both my surgeon and oncologist nothing showed up. Then 4 years later I went and had some further tests done which at the end of that showed secondary breast cancer – bones and lung – it was then that I decided that I had enough of work, I retired, I worked in a very fairly stressful industry of finance and commuting 3 hours a day and I decided to give it all away. I thought that's enough. I reassessed what I was involved in life and I had to reassess my health, my diet, exercise and all the things that I let slip while I was on the work treadmill.

Is there anything you would like to say in a message?

Breast cancer is not just about females. I think the challenge for us is to build and awareness program that not only includes the male but certainly a much more inclusive perspective about who is affected to try and get better outcomes for society in general. A lot of the stuff that we see and read at the moment a lot of it is lost and that in itself becomes you know quite problematic whilst in terms of giving our own feelings about it. I think if we can find something that is far more inclusive in its naming that not only brings males along on that journey and makes people more aware that it is a disease that can affect people other than females that's what it is all about. Because the more that we can have awareness the better that we have better outcomes. About 6:00 At the moment the outcomes for males with breast cancer are not that great and I think that is partly because we don't self-diagnose, we are not aware of it we leave it a lot longer as you know males don't like to go to doctors at the best of times so to actually get there and actually get there and do something about it earlier is what we are trying to do. The message should be to get out there and be aware that you can be affected and if you do have the symptoms go and do something about it. Don't leave it too late because the worse the outcomes are.

How do you feel this cancer has affected your life?

I think in some respects we have always been a close family, not just my own immediate family but my broader family and I think it's just made us sit back and take stock and made us realise what the important things are. It has certainly made us a lot closer. And made us more realistic about how precious life is and make the most of what you can do with it.

I don't think there is anything I need to ask you, you have really highlighted what it has been like, I think we are coming from a common plane. What we are looking for is something better for the future.

Exactly

If you could go back in time what would have helped you to avoid where you are now?

That's a good question. I guess a combination of things. I think certainly an awareness that breast cancer does affect the broader part of the community than just the females. I think I would have probably would have been, because we do have a history of breast cancer in my family. I think I would have been a bit more aware or responsive and I think I would have taken steps not only when I was first diagnosed but when I was diagnosed with the secondary so I would have been probably a bit stronger in my discussions with the doctor with my GP and I think that maybe that might have brought about some better outcomes, I don't know.

9:00 APPROX

It's not the questions, it's just the feeling that I get it makes me really sad to think that there are men out there that just don't know what's going on.

I think there's a lot of people like that, the males that are living with a time bomb ticking potentially, as people sit there with that time bomb the worse their outcomes are going to be. I think anything about trying to build an awareness program that says to these people if you have some of the symptoms you know get on to it straight away. It was interesting I remember after I had my mastectomy reading about Nick Greiner the ex NSW premier, and he was one of

the more high profile ones that sort of came out and said "Hey I'm a male and I have breast cancer" I thought at that stage there might have been a lot more push behind that, I went you beauty here's an opportunity somebody to make a bit of a statement who has a bit of power and influence but it did not seem to happen and I thought well that's a bit sad. At that stage I did not know what I could do about it. It was only that through some of the paraphernalia and views of males I receive that I started to get a bit of a voice and I thought well if nobody's going to speak up about it then it just going to keep on going the way it is so well every little bit of opportunity that I get along the way to try and put some more balance and perspective back into the discussion or argument I relish the opportunity.

You were saying before when you were diagnosed with secondary breast cancer you were given some information could you tell about it

About 11:10 Yeah I have been on the mailing list for a while now I managed to pick up some of their other material. They did send me out which is called "Hopes and Hurdles" and it is a specific mailing that comes out with information for secondary breast cancer sufferers and just recently I received a lovely mail from them to say hey and all this counselling we are going to do for you now because you are a secondary breast cancer patient we will make this available for you. But it was all pink and it was addressed Dear Robert and all the wording throughout was as females, though I went, you know what you've lost me already because you are not including me in the discussion and I wrote back to them straight away. Luckily I had a really good response back from them and she said you are right and straight away she has changed some of the language and the wording that she is using in her domain in BCNA she is a lot more aware

of trying to some more balance in the discussion as well. Its things like that you are just grateful to think that here I am suffering the same disease through, I guess, an organisation that is tied to those breast cancer networks Australia. Yet I don't feel part of it when we are aside with a token information buried down about six layers in a book about men getting breast cancer.

That's not good enough for me. It's got to be we are part of the same health issue here let's get serious about it.

About 13.00

Absolutely, I am sick of pink I can tell you I know I speak to some others as well that something that they have a big problem with as well. I think that straight away pushes it out there in the community that the colour pink is associated with female therefore it is all about females. Yeah, I would love to see something that is a bit more universal. Even when I look at where America is I've done some work with the Male Breast Cancer organisation over there they have the little pink bow but half of it is blue and half pink and I thought that's nice that's a lot better than where we are in relation to our symbols and stuff that goes with it as well but even that it's just pink and blue so it's male and female I think they are probably a bit more realistic but there are people that are potentially missed in some other microcosm of society who may not necessarily get a voice out of that

Is there anything else you would like to add?

I guess just from a personal experience I know something that feels still surreal even though it is five years on and it feels as though it is happening to somebody else and it feels as though I am not being true to myself anymore in my discussions with my friends and family and some of the organisations that I have been dealing with when I know what my outcome is I know what I've got but there's something inside of me that defines me and I think that is part of the reason why it still feels so surreal because I don't want this thing called breast cancer to define me.

And take a moment to go on retirement and enjoy my time because to be honest nothing has significantly has changed. I have one less breast and I suffer from lymphedema but the rest of it is great No bone pain from my metastases my tumours in my lungs have shrunk from what they previously were. I am in a much better place in relation to exercise, health, diet and life is good.

Appendix B4: Video Transcripts

Conversations (2016) snippet video

Karlee

I was sitting in the waiting room of the hospital surrounded by 60, 70-year-old women and I had just been told that at 3 days before I turned 22, that I was getting my breast chopped off. I broke down and I was sobbing the lady came out and had to take me to a separate room That was definitely the hardest part when I was diagnosed.

Rob

I think being a male with breast cancer is quite an interesting journey to use an old clique. And I think these a feeling that somewhere along the line we're a bit of a forgotten species. That this thing called breast cancer is really a female disease and I think along the way there's a feeling, of once you have been diagnosed and go through the whole process like I did mastectomy, chemotherapy, radio therapy there's a feeling of a loss of masculinity.

Lisa

My self esteem has taken an enormous hit since being diagnosed and treated for breast cancer. I am physically a vey different person than I was. I have had my breasts removed, I have had all my lymph nodes removed, I had chemo, now I have permanent hair loss. I have had my ovaries turned off I am in complete menopause and my hair has never regrown to what it was precancer. All of the aspects of my femineity have been stripped away.

Leia

I think the biggest shock is when you do see yourself like that. You haven't recovered from surgery, the movements are not quite there because of your muscles and things, you haven't had any expanding yet, so I was almost concave and wrinkly. The hair was gone, the nose hair was going, it felt like rock bottom, yeah, it was crap.

Sam

I was told I had to have chemo, because originally, I wasn't going to have chemo. Now I was faced with okay, so what about children, which was the hardest part, I was told I wasn't going to be able to have children now. I am 28 not and I've got there's man many years, I have got plenty of time for it to come back somewhere else. I think that's what worries me the idea that they didn't even pick up those two tumours. In the MRI they didn't pick them up so I guess I am worried about things being missed.

Briohne

My friend that passed away said to me when I finish the radiation in 6 months you are going to feel so much better again, and you know what 6 months after that double it, so you will feel better again. And 6 months after that it will be a distant memory. You'll talk about 2012 being the worst year a difficult year but it will just be a memory.... And that was true for me up until last year, when a pain in my shoulder and my spine I kept thinking was because I was getting old wasn't just that. It was because it was here again, and I am so cranky that that's the truth. Well anyway here it is I have bone metastasis in my spine and skull and shoulder.

The main one being my right shoulder and I am right-handed that's the one that gives me the most pain. So, three months before that shoulder pain showed nothing, then the one in June showed there was. Who knows how these things happen, is it one of them floats around hiding and lodging in my bone growing there doing that for 2 years 3 years whatever it was between the first time and the second time, I don't know but here it is... It's not going anywhere this time and while I am in a honeymoon period of with fairly good health and pain management but very mobile and very energetic, there will be progression. It's almost comforting to know what will happen. It's not if cancer will come back – it's back this is the reality and I know what's going to happen next. I am going to have 33 months of this honeymoon there will be progression, then we'll argue with progression till it wins and we'll deal with the horrible, or my family will because for me I just get to slip into the abyss. For them they have to deal with the moving on from there and they'll do that well because their, well I hope that I have taught them to count their blessings because there is always good and I don't believe why me. I believe in why not me, because anytime I think why not me I have a husband who can care for me and love me I know women that don't. I have children, I got the have them straight out of high school a couple of them are going to be adults. When it's the worst for me all of them will be adults so why not me instead of someone with younger children.

Jane

It would be great if nobody died from it but its too complicated and because it hides it's a funny little thing breast cancer hides and its very hard because it spreads and it doesn't matter how vigilant they are it can happen so quickly. But making it so that it is more of a chronic disease that can be dealt with that can be like a few people I know now the have no evidence of disease they have to keep up with their treatment that keeps it at bay and it means they have a longer life. I that's what we really need to get our heads around first and then the next step.

Edited Text for Managram (2020)

Rob: I think being a male and having breast cancer is quite an interesting journey to use an old cliché. I think there's a feeling that somewhere along the line that we're a bit of a forgotten species. That this thing called breast cancer is really a female disease and I think that somewhere along the way there's a feeling of once you have been diagnosed, and you go through the whole process like I did, you know mastectomy, chemotherapy and radiotherapy, that there's a feeling of a loss of masculinity.

Rod: It took me three visits to my GP and I thought I know there's something wrong with me, but she kept saying no, there's nothing going on there, but the third time I was insistent on a scan and in this case an ultrasound because they're a bit easier for men.

So, most men find their cancer by feeling a lump or having a nipple discharge. Obviously once the discharge is there, it is a lot more serious than an inverted nipple so the three things are, inverted nipple, discharge, or a lump the size of a pea.

Rob: if it wasn't for my wife, I wouldn't have even self-diagnosed. As males don't have breasts and don't suffer from breast cancer is the normal thought process. It was only that

my wife noticed an inverted nipple on my right hand side and suggested I go and talk to my GP

Breast cancer is not just about females. I think the challenge for us is to build an awareness program that not only includes the male, but certainly a much more inclusive perspective about who is affected, to try and get better outcomes for society in general.

Rod: There is a group of LGBTQI who are people who have got together to make their community aware and I would put them in the same category as men and women, in that they are spoken about as genderless people who get this disease that people get breast cancer and the sexual orientation, the gender, is not the biggest part of it.

Of the 150 men in Australia each year diagnosed, I might meet 1 or 2 or them, and I am on all the public blogs that deal with breast cancer. There is a move for some breast cancer charities to be inclusive of the men now, but those men are still being diagnosed, still being treated, but they are not coming out.

I feel they won't come out until they feel comfortable. Who would? It is a bit like gender inequality, and we need to feel like we are part of the cohort, we need to feel like we are going to be accepted as men with the disease, and not put in a corner, or whispered about. We need to belong to the breast cancer community.

Researcher: Do you think that it might be connected to the colour pink?

Rob: Absolutely, I am sick of pink, I can tell you, and I know I speak to some others as well, that something they have a big problem with as well. I think that straight away pushes it out there in the community that the colour pink is associated with female, therefore it is all about females.

I don't feel part of it when we are an aside with token information buried down about six layers in a book about men getting breast cancer. That's not good enough for me. It's got to be we are part of the same health issue here. Let's get serious about it.

Rod: I have a BRCA I variation of unknown significance. I was tested for the BRCA genes because my mum died as a younger woman aged 41. I have a daughter and a son. Very quickly after I was diagnosed, my daughter was put into a program, a public health program that calls them back each year for an MRI, for a physical examination, and an ultrasound. Very good surveillance for her, and she is very happy with that. My son, after all his father had breast cancer, his grandmother had breast cancer, has no such program. He's on his own, he's basically, you know...he can check himself without a scan, but it seems like that's a discrimination that's really not fair.

Rob: At the moment the outcomes for males with breast cancer are not that great and I think that is partly because we don't self-diagnose, we are not aware of it, we leave it a lot longer, as you know males don't like to go to doctors at the best of times.

I think there's a lot of people like that, the males, that are living with a time bomb ticking potentially, as people sit there with that time bomb, the worse their outcomes are going to be. I think anything about trying to build an awareness program that says to these people, if you have some of the symptoms, you know, get on to it straight away.

Appendix C: Empirical Data from Coding Journal (2020-2021)

% who did not know men could get breast cancer

"Most people believe this is a woman's disease and men are not targets.... I am well educated but still I DID NOT KNOW men could get this disease."

Stu Wein 2015
"...my family friends and collegues,...had no idea that men could get breast cancer."

James Michael (Mike) Wyatt 2019

In the 164 stories I analysed 27% made a direct reference that they did not know breast cancer existed in men. I excluded from the tally any references to a need to check their breasts, other peoples lack of awareness. The focus reading was to tally men that had no idea that men could get breast cancer.

19

"I struggled with the fact I had male breast cancer and was telling everyone I had a tumour on my chest most people perceived [it] as a women's disease." Stephen Sala 2016 "... the stigma of breast cancer started in the hospital... ... A man just didn't get a women's disease...." Lee Simmons 2018. "I felt ashamed and embarrassed" Nathan Spencer 2019 "To me this was a loss of my identity. I couldn't look in the mirror. When I did there was an image of someone 1 didn't know ... " Jerry Troyer 2015. "He suggests using samitary napkins because of their absorbancy; more de-masculinization" Jim Tuffield 2019 The stigma associated with cancer in my community and country is generally negative." Antonio Venturini 2017 A man with breast cancer may strugge do to the stereotyping of it as a "women's disease". 16 felt embarrased, ashamed or in denial after diagnosis of breast cancer 12 called it a "women's disease" or treatment only based on women told of the stigma as health care facilities were targetted for women. 12 felt demasculinization as images and treatment literature was female orientated. 4 told how medical staff assumed the appointment was for their wife. 8 references of stereotyping found in previous categories

"I wonder sometimes if a simple name change of the medical procedures might help
men talk more openly about their bodies. I am
thinking that a 'man-o-gram' might convince
more guys to have their breasts checked,
especially the over 60 group like me, statistically
found to be most likely to contract the
disease."

Khevin Barnes 2017

"chest cancer"

Dr Mathew Knowles 2019 in New York Times 3.10.2019

"chest cancer" Rob Fincher 2016

"Protect The Pecs" Steve Del Gardo 2014 "Guys go to the gym to work on their pecs, not their breasts." Marc Futterweit 2015

"I tried hiding it or calling it chest cancer

Jason Goldstein 2016.

"I would say 'I had a tumor in my chest." Jim Howey 2016

1 analysed 164 stories and added 2 from other sources. Of these 166 stories 6 made reference to their cancer not as breast cancer' 3.6%

50

Diagnosis timing

To delineate the truth 1 read the stories then tallied in the table below:

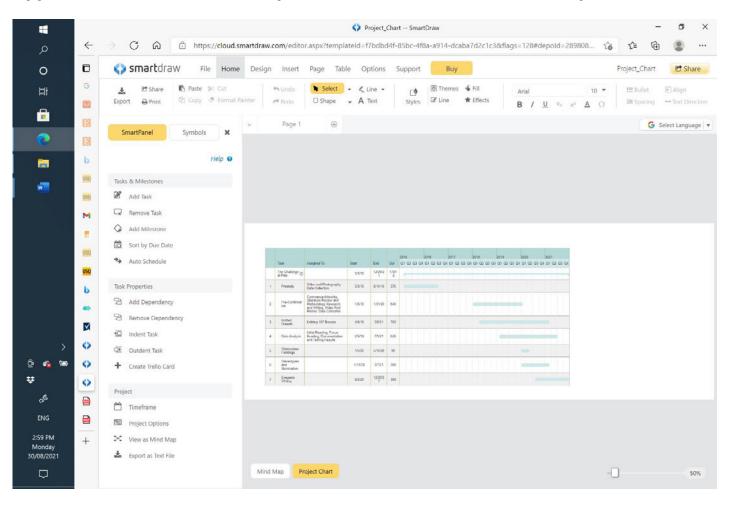
- doctors who minimised or did not send patients for investigation
- patients who delayed going to the doctor because:
 - did not know men could get disease
 - knew men could get disease

were proactive and doctor sent patient for investigation.

Piagnosis Timina		Number	%	
Poctor delay	delay.		19 11-4	
	unknown	19	11-4	
patient delay	known	5	29	
3	not specified.	14	8-4	
other insisted to goto doctor		37	22-2	
proactive		69	41.3	
Unknown diagnostic process		3	1-8	
metastatic at diagnosis		1	0.6	

52

Appendix D: Timeline for competition of Creative Work RIMS Report



Appendix E: Exit Survey Rod Ritchie



University of Southern Queensland

Project Details

Title of Project:

Human Research Ethics Approval Number:

Information for USQ Research Project Review and Exit Survey

The Challenge of Pink

H19REA060 (v1)

Research Team Contact Details

Principal Investigator Details

Ms Alyson Baker Email:	Mobile:
Description	i losiici
Supervisor Details	
Assoc Prof Janet McDonald	
Email:	Telephone:
Dr Beata Batorowicz	
Email:	Telephone:

This project is being undertaken as part of a Doctor in Creative Arts Project. The purpose of this project is to:

- Offer new strategies for awareness campaigns by highlighting the male, young (between18 - 40) and older women's (over 75) voices in visual and oral storytelling.
- Raise awareness of male breast cancer by creating an inclusive representation of breast cancer in visual and oral storytelling.

• Educate the general public to advocate for their personal health care through interaction artworks in a palatable yet realistic framework.

The research team requests your assistance to share your breast cancer story to the public. It is important to give a realistic viewpoint; the stories will be exhibited in various locations, may be published in academic and non academic journals as well as being shared on a website and Facchebook Page (Breasts and Chests). Video and/or audio of interview and/or transcription of the interviews or male photography may be shared with the National Breast Cancer Foundation, Breast Cancer Network Australia and Medical Training Institutions for educational and fund-raising purposes.

Please note that your participation in this project has been entirely voluntary. If you do not wish to include any images or text from interviews you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. You may also request that

Page 1 of 4

any data collected about you be withdrawn and confidentially destroyed. If you do wish to withdraw from this project, please contact the Research Team (contact details at the top of this form).

Your decision whether you take part, do not take part, or to take part and then withdraw, will in no way impact your current or future relationship with the University of Southern Queensland.

Expected Benefits

It is expected that this project may not directly benefit you, however, it may benefit future patients, the general public and medical practitioners. This research project explores the stories of people who have been diagnosed with breast cancer and the many different choices they have made in regards to their surgery and adjunct therapies. It is through telling these stories that I hope to open up a dialogue about the diversity of people who have survived or are living with breast cancer, and their own presence in the decision making process about their own health care.

Risks

Sometimes thinking about the sorts of issues raised in the interview can create some uncomfortable or distressing feelings. If you need to talk to someone about this immediately please contact Cancer Council Queensland on 131120, Beyond Blue on and Life Line on for support. You may also wish to consider consulting your General Practitioner (GP) for additional support.

Privacy and Confidentiality

All comments and responses will be treated confidentially unless required by law.

The interviews will be in audio and video for the purpose of public exhibition, these will be close up face shots. If you wish to remain anonymous, audio only

will be recorded and your name will be omitted from any written university papers, articles, magazines or public exhibitions.

You will be provided with a copy of the video and written transcript of audio for your review and endorsement, you will be given 14 days to contact Alyson Baker with any changes you require. You can also opt out of the project at any time by contacting the investigator (Research Team details above).

The video and/or audio of your interview may will be exhibited in various locations, it may be published in academic and non academic journals as well as being shared on a website and Facebook Page (Breasts and Chests). The video recording may be used as an educational tool for educational for the National Breast Cancer Foundation and Breast Cancer Network. All participants will be invited to the public exhibition and provided with a copy of video and transcript of audio.

Any video and transcript of audio collected as a part of this project will be stored securely as per University of Southern Queensland's Research Data Management policy.

Consent to Participate

We would like to ask you to sign a written consent form (enclosed) to confirm your agreement to review artworks and give feedback in this project. Please return your signed consent form to a member of the Research Team.

Questions or Further Information about the Project

Please refer to the Research Team Contact Details at the top of the form to have any questions answered or to request further information about this project.

Page **2** of **4**

Concerns or Complaints Regarding the Conduct of the Project

If you have any concerns or complaints about the ethical conduct of the project you may contact the University of Southern Queensland Manager of Research Integrity and Ethics on +61 7 4631 2214 or email researchintegrity@usq.edu.au. The Manager of Research Integrity and Ethics is not connected with the research project and can facilitate a resolution to your concern in an unbiased manner.

Participation Review

Thank you for participating in this research. Your input in this project is valuable, the researcher would appreciate your feedback.

ullet I am a direct participant in the research, who was interviewed, and video recorded with photography $\boxtimes Yes/\square No$

I have reviewed the poster, palimpsest, copper stereotypes and watercolours artwork created for this project and endorse it for public exhibition.

•	I consider that the exhibition of the creative outcome reviewed for this research may raise awareness of the diversity of breast cancer patients and the issues some breast cancer patients face.
	⊠Yes / □No □n/a
•	I feel it would be valuable in sharing the creative outcomes reviewed for this research with medical students and breast cancer agencies to raise awareness of the issues faced by some breast cancer patients.
	⊠Yes / □No □n/a
•	I would like the following amendments to the images created for this project (please state below) and request that I view the artwork again for review prior to exhibition.
	□Yes / ⊠No
	Any alterations to artwork please state below

Statement of Consent

⊠Yes / □No

By signing below, you are indicating that you:

- Have read and understood the information document regarding this project.
- Have had any questions answered to your satisfaction.
- Understand that if you have any additional questions you can contact the research team.

⊠Yes / □No
⊠Yes / □No ⊠Yes / □No
Page 3 of 4
Participant Name Rod Ritchie
Participant
Signature

Date 1 November 2021

Thank you for taking the time to help with this research project. Please keep this sheet for your information.

Appendix F1: Email to Women's Imaging Centre 22/10/2021



Male breast cancer poster and suggestions

Hello,

I am a doctoral candidate at the University of Southern Queensland majoring in Creative Arts and a breast cancer survivor. Over the last three and a half years I have been exploring male breast cancer through artistic investigation. I have explored how men feel having breast cancer and have created artwork to include male images in the dialogue of breast cancer. I am contacting you to see if you are willing to hang a poster in your waiting room to raise awareness of male breast cancer.

In collaboration with Prof. John Boyages AM, internationally recognised radiation oncologist, breast cancer specialist and author of "Male Breast Cancer: Taking Control", and Teneille Grace, graphic artist, we have made an educational poster to raise awareness of male breast cancer and make suggestions on what to do if someone notices any changes in their breasts. I have attached a copy of the poster which may be printed on A4, but if you require a A3 or A2 size please let me know.

I also found during my investigation that a diagnosis of breast cancer may contest a male's sense of masculinity. Would you consider renaming the "Women's Imaging Centre" so that it is more gender inclusive to reduce the stigma for male patients who may present for diagnostic imaging?



Appendix F2: Email correspondence NBCF 21 October 2021

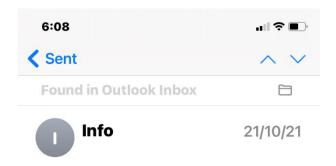


Alyson Baker artwork research in breast cancer

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I have also followed up on a hunch by one of my participants in this research who asked if there was something medically that could help men, so I have investigated some medical journals. What has emerged is that there seems to be biological differences in male and female breast cancer. Lordso et al (2017, p. 289) state, "It is indeed a distinct disease, with its own peculiar biological and clinical features." Muller et al (2012, p 787) also found that despite similar stage of diagnoses, male patients had a poorer response to treatment and a lower survival rate than female patients indicating that male breast cancer may be different to female breast cancer. Losurdo et al (2017, p. 290) explain "in the best interest of patients, a better global strategy to study male breast cancer prospectively is strategy to study male breast cancer prospectively is strongly needed." As an example, Wibowo, et al (2016, p. 784) state that there are no long-term rigorous studies on the use of tamoxifen in men. My arts practice aims to raise awareness and advocate for male breast cancer; although it appears that male breast cancer needs further research, I am not within the medical field. I would however suggest that the National Breast Cancer Foundation explores how male specific breast cancer research could be implement specific breast cancer research could be implemented.

I am happy to share the artistic outcomes of my
research for awareness raising and advocacy for male
breast cancer. In collaboration with Prof. John Boyages
AM, internationally recognised radiation oncologist,
breast cancer specialist and author of "Male Breast
Cancer: Taking Control", and Teneille Grace, graphic
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PH: 0420828939 I W: https://alybaker.myportfolio.com/alyson-bakerl http:// 0000-0003-3169-6381 IIII



Automatic reply: Alyson Baker artwork research in breast cancer

Dear Supporter, Thank you for contacting National Breast Cancer Foundation. We have received you email and a supporter representative will be in contact with you shortly, usually within 48 hours. (excluding weekends and public holidays) Thank you for your patience. National Breast Cancer Foundation Level 9, 10 Barrack St, Sydney 2000 GPO Box 4126 Sydney 2001 Web:

www.nbcf.org.au



Appendix F3: Email correspondence to BCNA 21/10/2021

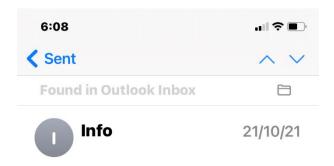


Alyson Baker artwork research in breast cancer

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www.nbcf.org.au



Screen shot Reply NBCF 21 October 2021





Male breast cancer poster for review and promotion

Dear Alyson,

Thank you for your submission to Breast Cancer Network Australia to review and promote your poster on male breast cancer.

We have sought feedback from men diagnosed with breast cancer in our network and received the following responses to the poster:

- "The poster is good and to the point. The photo makes it real. I think people will stop and read the detail so it will be effective."
- "That's me on the poster and I am very pleased with the final result."
- "I think that it is a little too explicit, for lack of a better word. I understand the need and importance of raising awareness on this issue, and that the 'shock-factor' could be an effective way to do it, but this may be too much. I am also not sure if people would realise that this person had a mastectomy/lumpectomy, in which case you would lose some of the effectiveness. This is just my personal opinion, and I should add that I am not strongly opposed to it."

We plan to promote your poster in the next edition of our Health Professionals Network news in February 2022, along with other resources on male breast cancer including Prof. John Boyages book "Male breast cancer: Taking control." For further information or permission to use the poster, can you please confirm the contact details for Health Professionals to use in these instances, so we can include this in the promotion in the eNewsletter?

Wishing you a relaxing and enjoyable break over Christmas and the New Year.

Kind regards Nicky



Nicky Muir | Policy and Advocacy Project Officer NMuir@bcna.org.au 293 Camberwell Rd Camberwell VIC 3124 1800 500 258 | Facebook | Twitter bcna.org.au

Breast Cancer Network Australia is Australia's leading consumer network. We **connect, support** and **empower** Australians affected by breast cancer. Visit **bcna.org.au** to explore everything that we do.

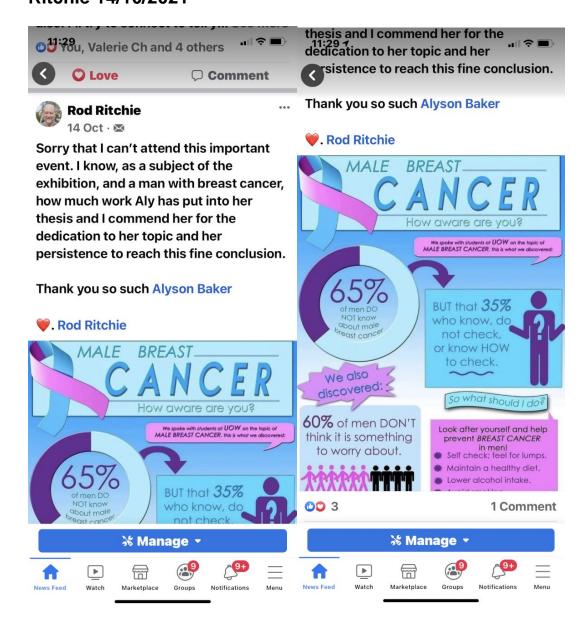
CONNECT. SUPPORT. EMPOWER.



Appendix G1: Gold Coast Exhibition viewer feedback Carol Darcy 16/10/2021



Appendix G2: Gold Coast Exhibition viewer feedback Rod Ritchie 14/10/2021



Appendix H1: Prof John Boyages Review of Poster (2021)



RE: Review of male breast cancer poster

Hi Alyson – this is excellent. Well done!!

Thoughts (mostly not essential)

1. Should you consider "first person" (I think it's called) to make it more personal.

e.g A lump in "your" breast, A discharge from "your" nipple etc

Not sure of the second one. Is it "shape and appearance" versus "shape or appearance" (again not essential)

Pain is a tricky one and so non-specific and not a common feature of breast cancer

Maybe "Persistent pain in your breast"

Re the Ultrasound- it's the first step but we don't want to give the impression if that is OK that nothing further should be done.

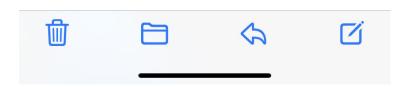
It is a good simple message though.

Perhaps Consider

Ask for a ultrasound and discuss a biopsy

Prof. John Boyages AM

Radiation Oncologist and Breast Cancer Specialist



Appendix H2: Dr Julia Pitcher Review of Manogram (2020)



On 17 Jun 2020, at 1:49 pm, Julia Pitcher < julia.pitcher@deakin.edu.au > wrote:

Hi Alv.

I've watched both videos a couple of times now. I found the content really interesting, although I found myself wanting to hear more than just the two stories. Interestingly, I took in much more of what the two men were saying in the calligraphy/crochet video with the voices, than I did with the actual vision of the men. I think this was partly because the head shot of the second man was difficult visually because he was so close to the camera. The content of what they are sharing is very good, and I think young doctors and advanced medical students will find it useful and educational.

I'm slightly ambivalent about whether they will get the significance of the nippleless, genderless breast, or indeed even work out what it is without some sort of cue. Are you allowed to give the film a title that could drop the hint?

Let me know if you'd like me to answer more specific questions.

cheers

Julia

Julia B. Pitcher, PhD

Associate Professor (Paediatric Neurophysiology) HDR Co-ordinator (Barwon Health, Australian Animal Health Laboratories, Warrnambool and Hamilton campuses)

School of Medicine Deakin University

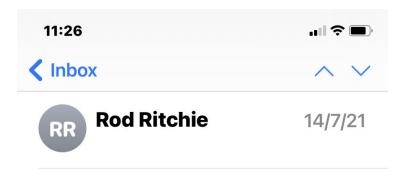








Appendix H3: Review by Rod Ritchie of artwork on Digital Creative Portfolio 14/7/2021



love your work

Hi Alyson, Wow, you've been busy researching and creating art!

I like your concepts, including the quotes, the research behind them, and the finished work.

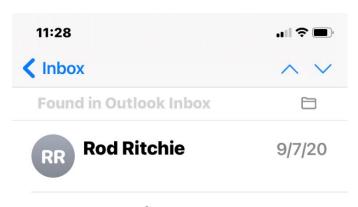
The poster looks great, I'd have to say!

I hope things are well for you. This project has been a long slog and youve had your own tragedy to content with.

I'm fine, very busy with local politics and social media for the bc stuff. Here's a recent podcast:



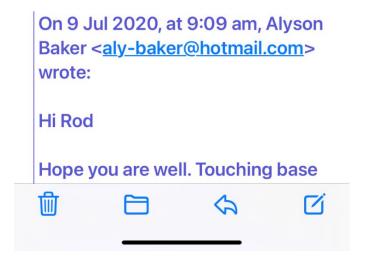
Appendix H4: Review by Rod Ritchie of *Sword Fighter* (2020) 9/7/2020



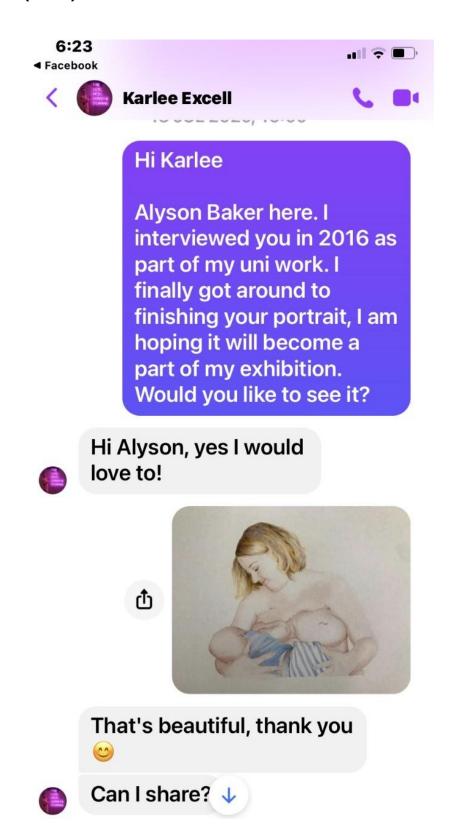
Re: Portrait

Wow, Alyson, that's a fantastic and meaningful work of art.
Congratulations.

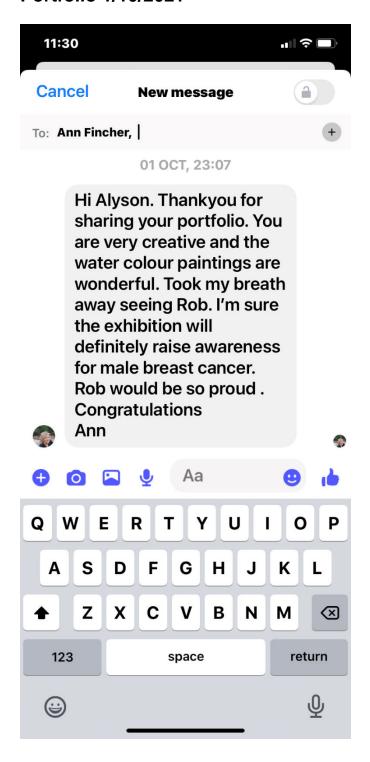
Dtay safe, Rod



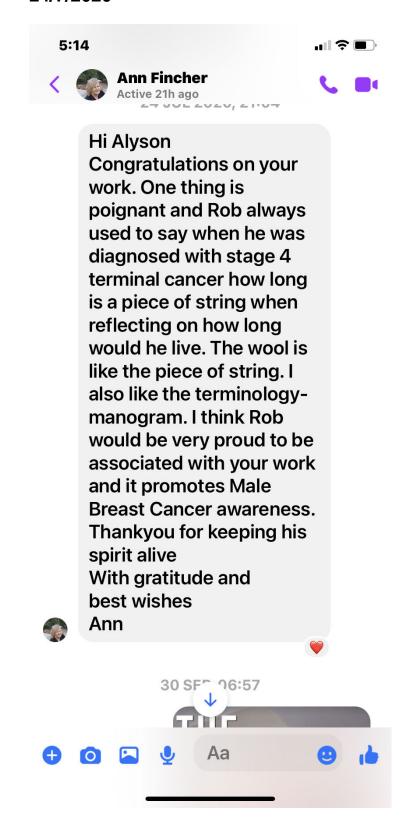
Appendix H5: Review by Karlee Excell of *Karlee and Eli* (2020)



Appendix H6: Review by Ann Fincher of Digital Creative Portfolio 1/10/2021



Appendix H7: Review by Ann Fincher of Manogram (2020) 24/7/2020



Appendix J: Rod Ritchie's Ultrasound



Appendix L1: Karlee Excell Consent



University of Southern Queensland

Consent Form for USQ Research Project Interview

Project Details

Title of Project:

The Challenge of Pink: A mixed media arts-based research project

collecting and collating survivor stories of breast cancer.

Human Research Ethics Approval Number:

Research Team Contact Details

Principal Investigator Details

Ms Alyson Baker

Email: Mobile:

Supervisor Details

Assoc Prof Janet McDonald Email: Janet.McDonald@usq.edu.au Telephone: 0746311232

Dr Beata Batorowicz

Email: Beata.Batorowicz@usq.edu.au

Telephone: 0746311115

Statement of Consent

By signing below, you are indicating that you:

- · Have read and understood the information document regarding this project.
- Have had any questions answered to your satisfaction.
- Understand that if you have any additional questions you can contact the
- Understand that the interview will be audio and video recorded. That a photograph was taken of my head and nude torso and will be used to create a watercolour painting
- I understand that I can participate in the interview and be recorded in audio only and my name can be re-identified
- · Are over 18 years of age.
- I understand that any data collected may be used in future research activities. I understand that video, watercolour paintings and/or audio will be exhibited in various locations, it may be published in academic and non academic journals as well as being shared with NBCF, BCNA, on a website and Facebook Page (Breasts and Chests).
- · Agree to participate in the project.

Yes / DNo

Yes / ONo

☑Yes / □No

ØYes / □No

MYes / □No

MYes / □No

Page 1 of 2

Participant Name	K	a	rlee Excell	
Participant Signature				
Date	7	17	24	

Please return this sheet to a Research Team member prior to undertaking the interview.

Page 2 of 2

Appendix L2: Rod Ritchie Consent



University of Southern Queensland

Consent Form for USQ Research Project

Interview **Project Details** The Challenge of Pink: A mixed media arts-based research project Title of Project: collecting and collating survivor stories of breast cancer. Human Résearch Ethics H19REA060 Approval Number:

Research Team Contact Details

Principal Investigator Details Ms Alyson Baker Email: Mobile:

Supervisor Details

Assoc Prof Janet McDonald Email: Janet.McDonald@usq.edu.au Telephone: 0746311232

Dr Beata Batorowicz Email: Beata.Batorowicz@usq.edu.au

Telephone: 0746311115

Statement of Consent

B٧	signing	below.	vou are	indicating	that	vou:

	Have read and understood the information document regarding this project.	☑Yes / ☑No
٠	Have had any questions answered to your satisfaction.	⊠Yes / □No
•	Understand that if you have any additional questions you can contact the research team.	□/es / □No
*	Understand that the interview will be audio and video recorded. That a photograph is taken of my head and nude torso.	Øres / □No
*	${\rm I}$ understand that ${\rm I}$ can participate in the interview and be recorded in audio only and my name can be re-identified	Øyes / □No
*	Are over 18 years of age.	ØYes / □No
•	I understand that any data collected may be used in future research activities. I understand that video and/or audio will be exhibited in various locations, it may be published in academic and non academic journals as well as being shared with NBCF, BCNA, on a website and Facebook Page (Breasts and Chests).	Øyes / □No
•	Agree to participate in the project.	MYes / □No

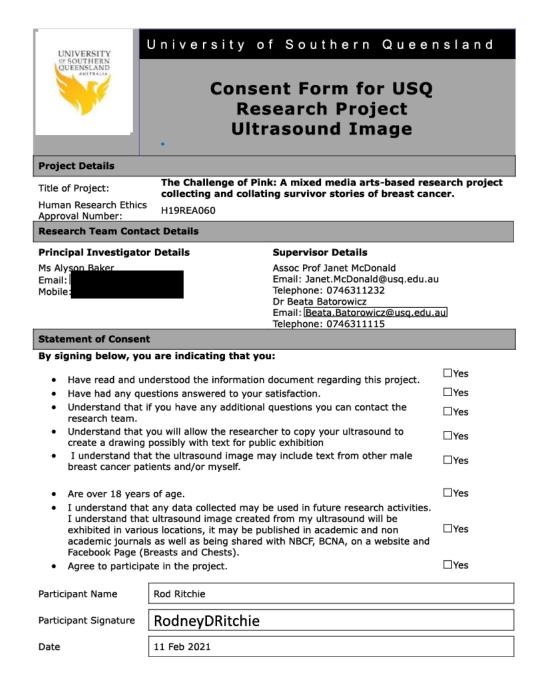
Page 1 of 2

Participant Name	Rod Ritchie .
Participant Signature	
Date	10 June 2019

Please return this sheet to a Research Team member prior to undertaking the interview.

Page 2 of 2

Appendix L3: Rob Fincher Consent



Please return this sheet to a Research Team member with an email copy of your mammogram image.

Page 1 of 1

Appendix M1: External Examiner Doctor of Creative Arts Exhibition Guide

The Challenge of Pink:

Subverting the current breast cancer awareness paradigm through visual and oral storytelling A Practice-led Research Project by Alyson Baker USQ Arts Gallery, School of Creative Arts, A Block Toowoomba Campus

The Challenge of Pink: Subverting the Current Breast Cancer Awareness Paradigm Through Visual and Oral Storytelling is a practice-led research project that explores the living experiences of male breast cancer patients and articulates the emotional consequences of their treatment in the form of mixed-media installations. The artworks generated for installation aims to redress the representational imbalance by providing an alternative public awareness paradigm that gives visibility and voice to male breast cancer patients. This project is intended, first and foremost, to create a platform where all gender of patients' issues are heard equally, coherently and in harmony. A further project aim is to create a body of artwork that speaks to a wider audience including medical practitioners, patients and their families, and breast cancer awareness advocates, of the need for more inclusive narratives of breast cancer awareness.

The artworks comprise 70% of the assessment, and all artworks are in accordance with Ethical Review H19REA060 (v2). Please refer to Gallery Campus Map attached for the positioning of key artworks with the following explanatory statements:

1. Standard (2018-2021)

The central artwork *Standard* (2018-2021) represents the number of men in Australia diagnosed with breast cancer is 2020. The collection of textile breasts was created over the course of the entire research period and has been exhibited in the form of a battle "standard". This artwork alludes to the statistics of male breast cancer and etched within the forms are my own story, my own artistic therapy of knitting to come to terms with my experience of breast cancer. *Standard* (2018-2021) provides a link between my own experience of the disease and that of the male experience, creating a bridge between *insider* and *outsider* research.

2. Illumination (2021) series and Stereotype (2021)

Foregrounded are two exhibition spaces which house the *Illumination* (2021) series and *Stereotype* (2021) series. These artworks shine a light on how men feel having a stereotypical women's disease. The *Illumination* (2021) series is interactive, the small torches may be used to shine on the ultrasound images to find theoretical categories of this research. While the accompanying stereotype plates in the *Stereotype* (2021) series document feelings of male breast cancer patients gleaned from reading their stories. In this space are the Artist Journals (2018-2020; 2020-2021; 2021) and Coding Journal (2020-2021); these form a documentation of the research process and data analysis for this project; please pick up the books and read through them. Together with the *Illumination* (2021) and *Stereotype* (2021) series I make transparent the Autoethnography and Grounded Theory methodology of data collection and analysis used in this research.

Surrounding the central exhibition of *Illumination* (2021) and *Stereotypes* (2021) on the left side of Standard (2018-2021) on the back wall are water colour paintings that provide an alternative to the female engendered breast cancer awareness paradigm. It is an inclusive representation of men and women, side by side, to allude to the diversity of people affected by breast cancer.

3. Flongs (2021)

The artwork *Flongs* (2021) on the opposing side replicate the entrenched paradigm of awareness in a paper mould traditionally used to make a copper stereotype plate. The implication is that if the mould is used the erasure for people, other than female, will be perpetuated. The *flongs* may be picked up and read, the text is a print of the stereotype; the experience is subtle like the marginalisation of men with breast cancer, in the current female-oriented paradigm of awareness.

4. Conversations (2016) and Manogram (2020)

On either side of the central artworks are video projections, which metaphorically bookend this exhibition. On one wall is a small video, *Conversations* (2016), which is a documentary video from my Honours degree work. The inclusion of the male voice during this research became the catalyst for my Doctor of Creative Arts. On the other wall is *Manogram* (2020) it is a recording of the only men to be included in the Breast Cancer Network Australia (BCNA) Summit in 2017; at this summit, men's voices were heard for the first time. Since this, the BCNA has included advocacy for men in their agenda.

The word *manogram* was coined from reading a story by Khevin Barnes, one of 167 analysed in this research, in the Male Breast Cancer Coalition (2021) website where he asks: "I wonder sometime if a simple name change of the medical procedures might help men to talk more openly about their bodies". The word *manogram* is knitted into the artworks to bind my experience with the male experience of breast cancer.

5. Poster (2021)

Near the entrance to the exhibition is a poster. *Poster* (2021) was made in collaboration with Prof John Boyages, internationally known radiation oncologist and author of *Male Breast Cancer: Taking Control* (2015), and Teneille Grace, graphic designer and breast cancer survivor. *Poster* (2021) has been distributed to the National Breast Cancer Foundation, Breast Cancer Network Australia (BCNA), The Women's Imaging Centre, and it is scheduled to be published as a resource on the BCNA Health Professionals Network in 2022. The intention is to distribute this poster to educate, raise awareness and advocate for the diversity of breast cancer patients.

6. *Artist Journals* **(2018-2020; 2020-2021; 2021)** and *Coding Journal* **(2020-2021)** The Artist Journals (2018-2020; 2020-2021; 2021) and Coding Journal (2020-2021) document the creative

processes and data analysis of this research. Pivotal pages are related to the artworks:

Artist Journal (2021, p. 40) is the design for *Standard* (2018-2021) while Artist Journal (2018-2020, p. 43) is the design rationale. Experiments for *Illumination* (2021) are recorded in Artist Journal (2020 - 2021, p. 38-40), while the description is in Artist Journal (2020-2021)

p. 18, 20, 21) while *Stereotypes* (2021) and *Flongs* (2021) are explained in Artist Journal (2020-2021, p. 22, 61). The inspiration for *Sword Fighter* (2020), one of the first watercolour paintings, is documented in Artist Journal 2018-2020 (p. 26) while the analysis of *Sword Fighter* (2020), *Karlee and Eli* (2020 and *Rob* (2020) are in Artist Journal (2021, 28, 29). Analysis of *Manogram* (2020) and *Conversations* (2016) videos, are contained in Artist Journal (2021, p. 22-27), and *Poster* (2021) is contained in Artist Journal (2021, p. 35, 36). The Coding Journal (2020-2021) is organised in theoretical categories of the data analysis, each tab relates to the motifs from the *Stereotype* (2021) series while the theoretical category name is in the *Illumination* (2021) series. The quotations in each section form the evidence for each theoretical category and some of the pivotal quotations form the text within the *Stereotype* (2021) and *Flongs* (2021) series.

NOTE: Please refer to Gallery Map

Appendix M2: Guide to Artworks: Floor Plan

