Study 17: Interview Transcript

Interviewee: “A” Participant: “P”

Participant ID: 013 Transcriber : Peggy Rowe

A: So the first part is pretty general Michael. I was wondering if you tell me a bit of background information about yourself. About your history and being diagnosed with prostate cancer and then the treatment you have completed so far.

P: Yes sure. I’m terrible at dates, I tend not to remember things if I don’t have to because it’s just the way my brain processes things. So I think it must be 3 years ago since the treatment. Probably diagnosed 4 months before? Probably 4 years ago that I was diagnosed. I had issues prior to that. Painful urination, pain at the end of my penis, painful orgasms, I would get quite uncomfortable but I just thought that was an age thing, you’d get strictures in you urethra and that sort of thing. So my father got prostate cancer, he was much older than me when I got it. So we sort of had blood test but I hadn’t had one for two years and I had to go to the doctor for inoculations for going overseas. He said I haven’t done your PSA for a while so we did that, it was purely routine but it came back very high PSA. I’d always had an above normal level, but it was always very stable and this one was very high. And my prostate exam was never very useful in the diagnosis. So that came back, he referred me to the urologist, he pretty much knew that I had cancer so he just did a biopsy which was utterly painful. So probably the first message out of that is, normally when I’ve had sedation or anaesthetics for minor surgeries it knocks me around a bit. I actually sleep pretty well, I had to go up to Adelaide to have a procedure done and I was going to drive back the next day. I knew it would knock me around a bit so I asked if they could go a bit light on the anaesthetic. He said yes I can do that for you mate. Anyway about half way though I more or less woke up. They had to do about 6 biopsies and I had to go through that, so my advice is, make sure you are sedated because it’s like someone stabbing you internally – absolutely excruciating. You know if you have to test yourself for diabetes or something and you have to prick your finger but you sit there because you don’t want to do it because you are such a sook? Well it was like waiting for that. So my advice to anyone is make sure you’re out, wake up and go well that’s over now I’m fine. Is this what you want?

A: Yes this is great, I was wondering what sort of treatments you had as well?

P: Well with that I had that test which obviously came back positive for cancer. He then suggested that I have brachytherapy because of my age. He then said I’ll refer you to another urologist because I don’t do them. So when I went to see the other chap he had to do several other test. I had to go to Adelaide to do a volume test, to test the volume of my bladder and to measure how much fluid I could pass through as urine. That was actually a cold wee in a bucket, so I had to travel the whole day to wee in a bucket. Which is literally what you are doing weeing a bucket through this measuring device – it’s quite funny because you have to have a full bladder and that tends to get a bit uncomfortable. So I did that one and I had to have a colonoscopy because I had some bowel dysfunction at that stage and they wanted to make sure that I had no bowel problems. Then he did something else I can’t remember – Oh, then I had to go back to theatre again to have a volume study of my prostate. But that was different. I used to put catheters in people and take them out when I was training as a paramedic. Our catheters were designed to have 10mls of fluid in the bulb end to prevent the tube coming out. He put 30mls in mine which is quite unusual and I was quite groggy, the nurse was quite surprised. When I was able to urinate I was able to take the catheter out so I could do a wee and then I was able to go home, but we couldn’t get the catheter out and of course I was half stoned. There was this lovely little girl down in my nether regions trying to get it out but she couldn’t quite work it out. Normally they would attach a syringe to it and draw more fluid out so that they could remove it. But I wasn’t thinking straight so I said look I’ll do this, the poor little thing was distressed at causing me so much pain and I was embarrassed having her there so I just ripped it out. It just about had me on the floor. So the other bit of advice is its best not to help the nurses. They can do things perfectly well. So I had that treatment and then CT’s , I had a lot of diagnostic work done and then once that came back I had to go and see him and he said yes you are suitable for brachytherapy because your prostate can’t be too big or too small. If it’s too small they can’t see it with the radioactive seeds and of course if it’s too big you get significant problems with swelling and urinary retention which means they might not get all of the cancer. So I just scraped in, my prostate was just on the edge of being too large and he said that’s all good. Got referred up to Tennyson, Dr Trans who is just gorgeous. She’s one of those hard working doctors, a really nice person and business like. Lovely lady I’ve got a lot of time for her. So I had a couple of visits with her, she just explained what was going to happen and I think that was the last of my treatments I actually had the brachytherapy – that was probably the easiest, it was well OK that’s done. It was just the lead up to this, which turned out to be just a day procedure which was really good because I didn’t have to go up to Adelaide for 5 weeks and I didn’t have to have radiotherapy – you worry about all these things- losing your taste. I’ve got a friend who has recurrent lymphomas and she hasn’t had her taste buds back for 18 months. I love food and cooking so I was rather pleased that I didn’t have to live in Adelaide.

A: Yes, I think you said on your email that you are Rural, so was that travel kind of frustrating or was it OK?

P: Oh it’s a pain in the bum. I don’t want to sound silly here..

A: There are no silly answers, it’s all good.

P: I’m quite well paid for my job so I can afford to do these things and pay for them. I’d hate to be poor on a health care card and have to catch a bus up and relying on places that the Cancer Council provide, which I didn’t have to use. I’ve seen some of my friends who aren’t so well off and then you have got pensioners and people with mobility issues and you see kids going up for their chemo so for me it’s not a big deal. It is an issue because you have to be able to stay with someone overnight and if you haven’t got anyone in Adelaide you have got to find somewhere because you have had an anaesthetic and they won’t give you the anaesthetic if you haven’t got anywhere to stay so you either lie and just go. I was lucky because I had places to stay. For me I’d try to make a day of it, you sort of get used to it. I always used to go to the central Market and pick up fresh oysters for my wife – she loves those. She doesn’t get flowers, she gets fresh oysters.

A: Well you have to do what you’re going to do. Fresh oysters work. I might keep moving us on so that we are not here all day, although I’ve also got plenty of time so I’m not in a rush either. Oh sorry finish off.

P: So most of that for me was pleasurable. Work was really good, although most of it I organised for when I was off shift. But I just look at my clients who go up and I feel sorry for them because the resources and infrastructure just isn’t here. There was a study being done into prostate cancer in remote Western Australia. We are talking here about really remote community, 3000ks to visit urologists in Perth. They were looking at how they could reduce the time away and to try and make it into almost a one stop thing. So to give you an idea. If you have a knee problem in here in Adelaide you can have the ultrasound on one day and go on a waiting list for surgery the next day. I think that’s what they were looking at in Western Australia for prostate cancer and they were trying to upgrade the GPs in urology so that they could be the eyes and the ears and the hands of the urologists because there is a shortage of urologists at present in Australia. We have these problems at work – we send people up to Glenside to be assessed for mental health problems and then how do they get home? People just don’t have the money. So the whole thing is an issue but for me it was just a pain in the bum.

A: Would you say that you view your health any differently as compared to before your diagnosis at all?

P: Yes

A: How do you think you view things differently?

P: I view my mortality quite differently. I shouldn’t because we deal with people who take their own lives, die early, die young, traumatically, but its never occurred to me, that it would be me. My cancer was probably OK . It was never going to kill me, but you don’t think like that with the process. Ive had people with prostate cancer who didn’t realise, they didn’t realise their symptoms, they didn’t bother going to the doctor, and then it was in their bones, and you are rooted pretty much. I have less worry about money, I don’t look long term at retirement, and longevity. If we have something we want to do, we go and do it. We’re going to Europe in 2 weeks time for five weeks.

I said to my wife, you spend what you want. If that’s the accommodation you want, that’s what we will do. It really doesn’t bother me now. Im not silly. Im not going to restrict myself. So if my kids want something. Yep go out and I’ll help you do it whatever it is.

That’s the biggest effect it’s had on me. Its probably self-realisation here. Im quite intolerant to others in regards to attitudes about things. We live in our little boxes and everything is rosie – but it’s not for other people. You have a little scare yourself and then you see all these other people – they don’t get concerned about others, they’re more worried about– quite self absorbed and forget what’s important. Like a good mate will say to you ‘Were getting rid of some stuff, I know you need it, you can have it for 60 bucks….its got to have a sale price to it. I get quite intolerant of that

*Repeat similar.* Probably not relevant to my health

A: Many things relate to your health and well-being – its quite broad.

P: My mental health has suffered a bit. There were other issues that occurred within work and family on top of that. Intolderant of that. Sometimes I think it’s my own perception. And it probably doesn’t relate to reality.

A: When someone mentions the word physical activity or exercise, what’s your first reaction.

P: Great, got to do it.

A: Can you tell me a little bit about what you like about it?

P: I’ve been exercising since I was 15, Im now 56. I still play competition sport (soccer). I haven’t played for 5 weeks. I hate running but Ive always done some form of exercise. Post end of season Ive slackened off. I’m feeling lots of aches and pains and I don’t have the same energy levels. If Im particularly angry/pissed off for some reason – just go for a big long run. It’s good for my mental health, it’s good for my mental health. I will play against 20 years olds in soccer, but I will play like a 20 year old, till exhaustion. It’s a really stupid thing to do but it’s just the way I am.

Got taken out recently - injury to ribs. Significant bruising and irritation to the muscles.

It’s good for me because the team and the club is trying to develop itself into quite a supportive group, sot he 15, 20 years olds will say how you going and stop and have a chat to you. The local police sergeant who I go on jobs with, he’s the coach and so we chat about stuff…..So I think exercise is great.

A: Are you doing any weights or strength training at the moment?

P: Last night. I have a little weight bench that I have that I use for doing my physio. My physio gives me exercises. I have an elastic band but I do basic weights. I know my knees are playing up badly so I do a lot of strengthening of my muscles around there and do some upper body stuff – light stuff. We have a rowing machine that we bought but we never really use it. I find at my age its not the right sort of exercise. I do 24 hour shifts, 4 days on. You cant just duck off for a run.

A: It sounds like you prioritise physical activity..you still make time for it.

P: Yeah, I’m slackening off and I feel like I need to go and do it…. I think its really important to do physical activity. It makes you feel better. You know what the weather has been like up in Adelaide. Been horrendous down here, rain scrawls day after day, so you cant go out, sit down a lot and that’s not good for you. I find that depressing.

A: Have you ever participated in a formal activity program before?

P: What do you mean?

A: Something run by an exercise physiologist or fitness instructor.

P: Not for years. When I was a young man in the army. Lots of aerobic classes. Do the circuit class. I used to enjoy that.

A: What might stop you from doing regular activities. You mentioned pain. Were there any treatment from the cancer itself that created barriers.

P: Generally no. After the treatment significantly. Just walking out the back, I needed to sit down before I fell over. Laying on the grass feeling absolutely stuffed. Don’t know if I picked up a bug at the time or it was the response to treatment because the symptoms I had post my cancer treatment, a number of them, neither my oncologist nor the urologist had heard……. Affects your vagal system a little bit. Don’t feel particularly well and cant urinate and intense pain for 30 secs to a minute but unpredictable. That all settled down and the treatment doesn’t stop me.

A: Can you tell me what might help you increase your physical activity levels?

P: Motivation, gale force winds. Seriously it’s the weather that affects my ability. Winter, dry cold freezing season. Ice. So cold going to training you didn’t feel like going outside. Bitterly cold, hailstorms but you go an play. Weather causes that. If you procrastinate like I do, post treatment you just get on top of what you need to do. Things then combine and it does make it difficult. Procrastination is my biggest killer.

A: Do you have a sense of the guidelines for physical activity are for someone of your age or health condition.

P: No I have no idea and I don’t pay attention to them. I have a fair understanding of my own physiology. Sorry, the organisation I work for for, the ambulance, has a SA Ambulance fit program. We actually have a sports physiologist come through, and nutrition, but not a lot of people take it up, but I don’t know if you’ve noticed but the older generation of Ambos are quite fat. The younger generation are all quite thin at this point. It didn’t quite catch on because we have had a complete demographic change over the last five years. I used it all the time but drifted off now. 12 month thing. They will tell me how Im going.

A: Its quite a physical job

P: Nah, its quite a sedentary job. You sit down a lot. If you are at a small station with a small load ou sit in the chair alot. In a busy station, half the day you are sitting in the ambulance. You are sitting on something. And if you are driving there are periods of intensity and that’s where we get ourselves into problems. Im part of the vertical rescue team down here that is infrequently used.

A: Is that someones dangling off a cliff somewhere?

P: Exactly. You cant just turn up and not have done some sort of maintenance exercise because you will tear a muscle. Wedo have support and I always found it quite helpful. But I just do my own thing. As long as Im not doing anything stupidly. I have a very good relationship with my physio over the years and so I go see her every 6 months. Or my wife will ring her and she will send me up some exercises. And that makes a huge difference going to a physio and somebody saying here are your maintenance exercises. I tell everybody that. If you’ve got an injury. Go see a sports physio or somebody who is sports minded who can give you the exercises to get you back to where you want to be, or for prevention. Ive used her exercises for years.

A: Im in the second year of my PhD program and me and my team are looking to design an online website that provides information and examples of exercises that are tailored and pitched to a person at where they are at.

Can you tell me a little bit about how you are using the internet at the moment?

P: I use it all the time for work and for research and planning my holiday at the present

A: Do you have specific sites that you like to visit because you find them really engaging or useful.

P: At the moment. A lot of holiday stuff but predominantly I use the internet for education. I’m an intensive care paramedic. Some of the skill sets, the drug sets, that we use the procedures that we use, you don’t use them very often. Some things you may never use. I find I’m doing a lot of the maintenance as I’m getting older. SO I use a lot of the YouTube sites. ? Medcram? What ever I find that is suitable for me. I use reputable sites, if that makes sense… Use for referencing and research. Ive actually stopped that for a while. Have spits and spurts. A good example for me. We recently got some new ECG monitors, previously we had capnography, we used to intubate patients to check their xxx levels, now we have the nasal placement CO2 monitors for watching peoples ventilations and how they are ventilating, and we are also meant to be using those monitors on those people who have been given sedation, and these are generally difficult non-compliant patients alot of the time. And so we got this lecture and its not something I use alot, I don’t sedate many people as in our treatment regimes, and we only just recently got it. But it was never introduced properly but its been introduced properly now and I don’t remember this so I spent time getting formal presentations on the internet. And getting it to where I needed to use it and to be comfortable – yeah that’s exactly how I use it. Yes, I’ve topped myself up, I’ve had my little learning. Cos I work sometime by myself and you don’t have that luxury of other people often and so Ive found that very useful.

A: So the video tutorials are something that seems quite useful to you?

P: Yes and engaging but I’m looking for specific stuff. Re diabetic ketone acidosis– You know the sites you want to go to, you know are really good, highly interactive or they present just like a lecture. SO that’s the sites I like in particular. I do a lot of research with words.

A: So it sounds like you enjoy the videos but do you have a preference for text, video pictures or a combination?

P: I love lectures. I prefer to have a video tutorial. So you look like you are sitting down and watching someone explain. But I do a lot of research anyway where I’ll go and get the written text because that is where you get the quality information. You get helpful hints a lot of the time. I listen to podcasts as well. I listen to a lot of medical podcasts when I’m working or when I’m running or driving….subjects that are interesting and what practitioners do on a day to day basis in reality as opposed to the lecture room.

From an exercise point of view, yeah Im not sure. That’s how I do it. Having an older brain and a slower brain, it does need reinforcing.

A: Hypothetically, if we took an on-line program and you were thinking about length of time and commitment, would you say that 8 weeks is an OK length or do you think it is too short or too long. What are your thoughts?

P: Seems like an awful long time. It depends on what you are trying to achieve, and what you want to do. That seems like an open ended question to me. To me 8 weeks sounds like a long time, a long commitment. If it was one day a week for 8 weeks, that’s probably not such a big deal. Its just remembering to do it.

A: Yeah, you have actually anticipated my next question. Hypothetically do you think a weekly, daily or fortnightly login would be more manageable? Perhaps fortnightly would be too far apart.

P: I’m probably not the best candidate to be asking these questions because I’m an all or none sort of person. So for me, if you were going to present something, I would just generally go and do it, then I get bored and stop and generally don’t go and do it again for a long time and then I would need to go back and do it again.

A: Hold that thought as it will lead onto the next bit. It’s all great.

P: The problem for me is I’m influenced by my work in the way the internet acts. SO if I had you writing it for me and it was looking the same for what I have to do for work, I will probably have a low compliance because we have multiple different departments that want to send out multiple education packages. There is that much occupational health and safety or multiple packages of doing crap drives me insane. I just can’t physically bring myself to do them. So everyone is using online as a training tool..its a very lazy form, so that’s influencing how I view things. So I’m not sure how that would fit with other clients.

A: That’s a really important point so thank you. Especially if you are feeling overwhelmed by all the other stuff that will be online as well.

P: I’m just frustrated. Have you watched the program Utopia on ABC?

A: No I haven’t.

P: It’s …on how frustrating things are run within government, and just like my organisation many years ago. I love it. It tells you why you don’t want to do things.

A: I will head onto our last section. These are our 2 internet scenarios. I will tell you the first one and get your thoughts and then I will tell you the second one and get your thoughts on that as well. So some websites are designed to offer ongoing advice so typically it would be delivered on a weekly basis and the user is asked to login and report how they are going in terms of physical activity and they are going to be given tailored feedback and then they are guided through the program and each week – say it went for 8 weeks – each of those weeks would unlock a new module so each module might have appropriate goal setting, resources that are really useful or examples of resistance training and because it’s tailored we are trying to pitch it to, for example, someone like yourself who is quite physically active, you’d try and pitch it at your level whereas someone who was starting from scratch, you would pitch it a lot lower. So what do you think are some pros and cons of that kind of program?

P: From my perspective, I probably don’t see a lot of use for me. I don’t mean to be rude and that’s why I explained my influence of work and I’m probably a little different to a lot of people, but it sounds like a lot of work I don’t want to do. Because I’m a person that looks at these sites for referencing, but you want to see somebody or talk to someone. I find that creates,…If you have a link with a person that is able to talk to someone in regards to, it would probably make it a lot more user friendly for me. So if I’m 70 and I have a question, I need to know that I am not going to have to go through a programmed system that is not going to be easy to use. If I have a cognitive dysfunction or something. Am I making sense?

A: Yeah – it’s a good point

P: Whether you are a 16 year old being diagnosed of cancer and you are motivated, your brain function is so much faster and quicker and you are so much more tech savvy. When you said it, the biggest fear for me would be the program designer. If its slightly frustrating to use, the compliance is minimal. For me, if it had the video component of it, like this is how you do something – that is quite easy to see.

A: So from what you seem to be saying, you like simplicity, easy to use, intuitive,.

P: Yes

A: The next idea is basically the same but instead of unlocking over time a series of modules, it presents all the information at once and you can pick and choose what you want to interact with but it still has the same amount of information – about 8 weeks worth and you still have the capacity to track your progress if you are interested. Eg Step count graph So it’s still got that approach but there is more choice.

P: That sounds better for me. The only reason I say that is, if you design such a site that was easy to use for the lowest common denominator – (person). Eg internet banking – If someone struggles with that type of website design, click, type in own information, visually easy to use and the feedback. You talk about increasing step count. Its almost like doing currency conversion on the computer. As soon as you put your figure in, you get the figure back in Australian dollars. So if I put down Ive done 3000 steps, instantly you get back and say well done or that’s the goal or maybe you are just 2000 steps shorter. You get that instant short feedback of information. A snippet of information and then you provide the areas that you can get deeper. The detailed stuff. This is how I would see it. That simplistic thing at the front that is easy to use. I know I can click on this and not be frustrated with it and get on. The log in site has to be simple. To be able to log in, its utterly frustrating with a lot of programs, and taking you to another site for logins (reference education sites for work), whilst you are already logged in. So if that process is simple and the person can do that, that’s easy. And then if they have a set of easy - maybe steps, maybe stretching, running, what ever the topic is, and they can go, Im really interested in my steps, or its hurting a little bit. Then you go “Is stepping hurting you” click here. Then there is a bit more information – if you want deeper information you can go and get it, or however it’s set so its easy to use. Lowest common denominator.

A: I think that’s a really good point. Thank you. What’s in a name. You want a program that is approachable but its not going to put people off so we have come up with some ideas. Could you so yes I like that one or that sounds dreadful. I would never click on a link that said that name. Just your first reactions would be great. My movement matters.

P: Doesn’t grab me

A: A stronger me

P: Not sure

A: I move more

P: I understand that one a bit better

A: Cancer fit

P: That’s a better one

A: Prostate cancer and physical activity online

P: So is it specifically about prostate cancer

A: Yes

P: I actually like the one before that. Cancer fit. Have you got prostate cancer, that’s the next one. I actually think if I was searching, cancer fit and I would click on that and it would say - For prostate cancer -. What was the other one

A: Prostate cancer and physical activity online

P: That doesn’t grab me at all.

A: Exmed – short for exercise medicine

P: No. I would go Cancer Fitness and you

A: Cancer fitness and you. I like that. If you have any ideas by the way, email me, that would be amazing. It’s a tricky area and lots of the other names are taken up by other research groups or government groups.

P: Like it could be Are you cancer fit?

A: Hey I like that

P: Am I fit to die - from this terrible disease. From prostate cancer with fitness and exercise, sexuality, sex from a man’s perspective can still be terribly important up to, talking to some of the blokes, up until their 70s I didn’t get very much out of my local prostate cancer support group. I went once and it just wasn’t for me. Because I was obviously the youngest member there. But one of the things a lot of them did talk about was they could have sex still and the impact of it. I had a physical instructor teacher in the army in 1979/1980. He was really about motivating people to maintain their fitness. Soldiers can be incredibly lazy. If we are building up to something, we take a lot more interest. I remember one day he had a sign up saying fitness is better for your sex life or you’ll be a better lover. In a battalion it’s really crude, rude, but it wasn’t, it was about do you want to improve your sex life, get fit. Some of this prostate cancer is also about your sexual health ( am I going to lose it). If you’re not physically fit, that also interferes. Whether you can use that as part of a catchy title or something that would grab men’s interest. Are you cancer fit, are you sexually fit. Are you fit post cancer for romance. Because seriously men will go….click. I’ll read that.

A: It’s a growing field in terms of prostate cancer survivorship literature. Its an area that’s not addressed very much.

P: My main scare as a younger man. That was a concern for me. Will I ever be able to? The big one for me was am I going to have to have a catheter for the rest of my life? These are unrealistic thoughts. But my father ended up with a permanent catheter because he had surgery. Its unlikely but people do think these things. So have you exercised. So there are some areas where you get people who have knowledge - Oh crap am I going to get this. Am I going to have issue with my bowels. I think it needs to be also pertinent to other things that are important if you interview other people where bowels are important. I thought about cancer, I thought about sex, I thought about urinary incontinence. Can you deal with this while exercise because I think to me, if you asked are you exercising but are you dribbling as well, because older men leak as women do and it get’s embarrassing. And I think these things stop people from exercising. To me they might be helpful links. I had a chat to a bloke, he passed away, but he wouldn’t go out anymore because he had a bit of dysfunction with his colon. He had periods of faecal incontinence which is quite manageable but he was devastated. I’m rambling but does that make sense.

A: It does make sense and I think motivation is a really good area to look at so that’s a really good point . Thank you.

P: The one on intimacy is probably one of the most significant ones for those who are still inclined to have sex. That will grab peoples attention and get some information. That’s the way I thought of it.

A: End of interview – thank you.