Study 16: Interview Transcript

Interviewee: “A” Participant: “P”

Participant ID: 11 Transcriber : Peggy Rowe

A: I was wondering *participant name* if I could start with a little bit of background information about the processes you’ve been through with the diagnosis of prostate cancer and any of the treatments that you have had so far.

P: I was diagnosed in 2012. And at the time I was diagnosed May/June I was diagnosed with oesophageal cancer. That came first. It was a form of Barretts that goes to cancer. About this time in the year, as we were just getting ready for a catering trip with the Waterhouse club, I was diagnosed with prostate cancer. Not diagnosed. I had a hard lump on my side of the prostate and they called me in to have a biopsy and I got the results of the biopsy the day we were supposed to be having a meeting with the Waterhouse club, and I had to go tell them, I’m sorry but I’ve got a major problem. I saw a *practitioners name* I think it was and he said to me look you’ve got 7 out of 8, one of the worst cancers you can have and it has got to come out immediately. He said I can’t use the robot, I have to do open surgery which means you will be in hospital for three weeks and I have to get two surgeon. I can’t do it all by myself. Ive got to have another one to help me.

I went to the meeting that night and told them Im sorry the trip is off, you are going to have to find yourselves another cook. One of the doctors there came up to me after the meeting and said to me, listen *participants name* you are not having open surgery. This is not unethical but what I have to do. This is the man you need to go and see. You’ve got to have the robot. So I went and saw *practitioners name* and he had a look at all the notes and everything else and decided he agreed with what *practitioners name* had said and he booked me in for about 3 weeks away and removed my prostate without any problems at all. Into theatre at 1 o’clock and coming out about 8 o’clock at night. And next morning at 8 oclock I walked out of hospital.

A: That’s a really quick turnover

P: All done, finished and I said to them when they came to get me, look I don’t really feel like going home. They said sorry we need the bed, you’re going home. The recovery on that was pretty good. Later that year I had the oesophageal cancer done. They got that out through the mouth.

A: So you’ve had quite invasive surgeries then, here and down there as well.

P: Then in 2015, I will just go back to the oesophageal cancer, Ive been having 6 monthly check ups on that. That’s an ongoing thing. Every now and then, they take a little bit more out. Last time he took a biopsy he said they look good. Anyway back to the prostate cancer, the PSA kept on rising – I can’t remember what the figures were, but they were pretty low but it was rising. So Richard Wells said I am going to prescribe you 35 days of radiation on the prostate bed. The prostate bed is actually the bowel because the prostate sits on the bowel. It took 12 months but I had that done in April 15, come about March 16, I started to bleed and Im still bleeding. The radiation cooks everything and the blood vessels all got cooked. *Practitioners name*, my chap that found my oesophageal cancer originally said to me that he could go in and use gas to burn the inside of the colon to get new skin growth that fixes the problem. I could go to the toilet and sit there and listen to blood coming out of my rectum. That’s how bad it was. Not good at all. I had to wear pads and all that type of stuff all the time. Anyway he got it to a stage where I was only bleeding 2 or 3 times a week.

A: So that’s a significant improvement

P: Absolutely

A: Then he got to the stage he couldn’t, because of the equipment he uses, he couldn’t quite get to the end so he sent me to *practitioners name* who uses formalin. It’s a preservative for when you are keeping a liver or something for long term. Explains treatment.

A: Yep OK

P: Ive had four treatments. Between the third and fourth treatment its actually got worse. Ive got an appointment to see *practitioners name* next Friday.

A: Hopefully you will get some answers.

P: I would like to get it to a stage. I don’t mind seeing a bit of blood, with my stool, that’s fine but when I have to wear pads to bed at night, because I daren’t pass wind without thinking its going to be a heap of blood, the sheets are all stained you know.

A: It must be quite frustrating and is it limiting in terms of what you could and couldn’t do?

P: It is. Very much so. I used to play golf with my son-in-laws but I haven’t had a game of golf for 5 years. You cant walk around – pass wind – find a big stain on trousers.

A: Do you find there are other things as well that limits your ability to be more active at the moment? Obviously that’s a major factor.

P: No, I still do most things.

A: You can obviously walk which is a good thing.

P: My age is a limiting thing. I’m now 73.

A: I would not have guessed. You don’t look it. Honestly thought you were about 60, so you are keeping well.

P: A lot of people tell me that which is good.

A: Do you think you view your health differently. Are you more active compared to before you were diagnosed with cancer

P: I’m a different person now. I have a different outlook on life.

A: I live each day as it comes now. I don’t plan too far ahead. I have things ahead Id like to do but if it doesn’t happen it doesn’t happen. Whereas before I could plan ahead and we’d head off and go and do it. Ive travelled most dirt roads in Australia. All the deserts. There is not much of the outback that I want to really travel anymore. I’ve just sold my boat. I’ve done the River Murray and the Darling as well. I’m going to buy a small caravan and we are going to do some coastal stuff. All my previous travels have been done in four wheel drives. You don’t really go to the coast line with four wheel drives.

A: No reall point. You need your four wheel drive for the sand dunes.

P: Yeah, dirt road, sand dunes, corrugations. Kimberleys and Cape York …Simpson

A: I don’t think you can survive out there without a troupee to be honest. So you are travelling alot now which sounds enjoyable. I’m a little envious. Maybe one day at the end of this PhD.

P: You’ll get there. A 76 year old lady driving her troupee by herself with her dog. I met up with her in Oodnadatta big roadhouse refuelling. Only 2 days ago we got a call from a lady who is 94 and she still drives her Toyota prado and if she can get someone to go with her, they can drive on the bitumen but Im going to drive on the dirt….. Described further

A: What a legend. Thanks for your responses so far. We will keep moving on about health and lifestyle, boring stuff. When someone mentions exercise or physical activity, what’s your first reaction?

P: I don’t need it. I have enough.

A: Yeah? Can you tell me about what you are doing at the moment.

P: Like yesterday. I’ve got a big shed, fifteen metres by nine metres. And I’ve got a loft in my shed. Up in my loft I keep all my camping stuff. SO going away now, I’ve just lifted all the stuff off the loft that’s got to come with me. Pitching tents and tarpaulins. Shade mat to walk on so you don’t stir the dust up, all those types of things. The gas barbeque, the gas oven, the gas stoves, burners,

A: So you are doing lots of reaching, pulling?

P: Yeah, and I had to fill up all the gas bottles and then the jerry cans for the generator and the jerry cans for the vehicle fuel and all that type stuff so I just said to the Chiro – he said you’re shoulders are a bit out, and I said well I’ve been carrying jerry cans full of fuel. If I wasn’t doing that I’d be in the garden. I got 15 fruit trees on our block. So there is always weeding and pruning and all that kind of stuff. I don’t cut the lawn, a lawnmower man does that type of stuff.

A: But there is a lot of lifting and bending and grabbing and pulling. Gardening is really hard.

P: And I don’t mind walking. I haven’t walked for a few months. Because I’ve got lazy I guess. But I guess now it is time to start walking again.

A: Now that the weather is starting to get better.

P: Yeah. My wife and I used to walk every morning for half an hour.

A: That’s really good. What happened that meant it stopped?

P: The weather and also my wife has a crook leg at the moment. I guess that’s more of an excuse than anything else. I could still do it.

A: At the same time it’s harder by yourself. Having someone to keep you accountable like no come on. I was wondering, have you ever participated in a formal physical activity program before?

P: No, I moved up the Mount Barker. About 12 months ago I started doing some stuff with the men’s group. Going to the gym and they go every Tuesday morning at 9.30 till 10.30 but you can go anytime you like if you are in that group so I used to go in earlier. And I rather enjoyed that but I don’t my shoulder in. I said to Physio’s name, Im sorry but I just can’t be bothered. So she said go see this guy at the hospital, he’s an expert physio on shoulders. Ive been seeing him for 12 months and my shoulder is just starting to come good. I couldn’t even lift a comb to my hair. This arm was just about dead. I can get my arm up to comb my hair now.

A: That must be such a relief to get that functioning back.

P: So Im getting my shoulder use back. I guess I will go back to the gym one day.

A: SO you found it not a bad experience.

P: Yeah. I quite enjoyed it. My wife told me off. Wasting your time.

A: Do you think there are barriers to activity. You mentioned the weather or of your wife’s not feeling that well either.

P: There is a barrier in that we are two, three km out of town. So you’ve actually got to get in the car and make an effort. Whereas if we were in a retirement village with a gym just there, that would be different. So that’s one barrier. Freezing cold morning, you don’t really want to go. Last year I did, all through winter. I went every day, every week Im sorry.

A: In terms of something that’s a facilitator. To be more active. Can you think of anything of the top of your head that’s helped you before.

P: Not really. Having someone like Physio’s name to work with you and say this is what you should be doing. That’s good whereas I’ve never had that type of thing before. Ive never had that type of assistance.

A: Yeah and its a professional support. Would it be different if it was a peer? Do you like the professional side more than if it was just someone who was your friend.

P: Either way, I’d be happy with either.

A: Do you have a sense of what the guidelines are for physical activity for some-one of your age or with your health condition?

P: No. I rely on what Physio’s name tells me.

A: Have you ever looked for resources before?

P: No

A: So this leads to the third part of our interview which talks about the internet and some of our research ideas. SO what my team is designing is something that Is meant to be online. It’s not a substitute for face to face. It’s meant to be more of a doing something in my own time as a kind of tool kit to improve your activities. So if you don’t know a lot about resistance training. This program will give you examples or ideas and stuff. If you dont want to go the a gym or you don’t have access to someone like Physio’s name. So the first thing I’m going to do is ask you some questions about the internet and then get your opinion on our research ideas.

A: Can you tell me how much you use the internet at the moment.

P: I don’t use it. Not at all.

A: Have you ever used it before?

P: I used to use it when I was working but when I retired in 2001 I said that’s it, the computer can stay on the desk.

A: You are done.

P: Done, finished. My wife uses it all the time. She does the banking, She does everything on the net. I don’t have to.

A: If you had to would you ever be interested to learn?

P: I probably would. Yeah. But its another thing I have to find time for.

A: Are you quite busy at the moment?

P: I’ve always got something to do. It is not very often I have a blank day in my diary. And I still keep a diary.

A: You are more busy in retirement than when you were working?

P: I don’t know how I found time to go to work. Honestly, it’s unreal.

A: When you have used the internet before. Say when your wife is talking about it. Are there things that you’ve noticed about websites that you like in terms of the way they are presented, information or if they’ve got visuals, pictures or text. Is there a certain way you’ve noticed, Oh that looks alright.

P: Yeah, I guess it doesn’t really matter. If there is some visual stuff there it’s nice. I guess there was a stage when I’d done my shoulder in which was back originally in 08, that’s how long Ive been putting up with it, I went to the backs in motion

A: Yeah I know that group

P: They gave me some diagrams and stuff like that. My wife printed them off on the computer.

A: So you had it there and you could follow.

P: Yeah so that type of stuff is good.

A: Did you do that from home?

P: Yeah

A: Was it good to have something home based so you didn’t have to go to the gym?

P: Yeah. Ive got a treadmill, Ive got a bike, Ive got a boxing bag. I do have some exercise stuff there.

A: Because not everyone has access to that stuff of course. That is really cool that you’ve got those things.

P: And if Im down in the shed and I get bored, I will go for a ride for a while.

A: Hypothetically if you were to participate in a program like this, do you think an eight week length is OK or is that too long?

P: 8 weeks. What’s a school term? 12 is it

A: 10 weeks.

P: You wouldn’t want it to be any longer than that. It depends on how active the program is, 6 could be long enough but if you are doing something different each time then

A: Yeah, it could be OK. Again hypothetically, do you think it would be better to log on weekly or fortnightly?

P: I think it’d suit me weekly. Every Monday morning at 8 o’clock or every Tuesday morning.

A: Yeah so you can build it into a routine.

P: Yeah and I would prefer mornings to evenings.

A: Yeah, if it is online you could choose to do that at 8 oclock in the morning, whereas if it was face to face you are kind of forced to.

A: So I am going to tell you about two different ideas about the way we would approach to the program. So some programs are designed to give ongoing advice. So if you log on once a week, you type information in and it will spit out feedback that’s relevant to the first information you give. Then there is modules or basically it’s a topic summary, so the first week might be an introduction, the second week might be about how to goal set appropriately. You can’t just say Im going to lose 30kg and leave it at that. You have to be very specific. For example. And it’s very logical so you would go A, B, C, D. So a logical progression. What are your thoughts on that kind of idea.

P: It has to be regimented. You can’t just have it ad-hoc. I think having it regimented is a good idea.

A: That’s really interesting. Because our second idea is the ad-hoc. It would be the same. That you would log-on and you’d give your feedback but you would get about 8 weeks of information but you could pick and choose what you read and what you would do. So it’s less structured. Do you think that is something you would be interested in?

P: If I have to put my mind to it, and I know Im going to do it, I know its for 8 weeks and its regimented for 8 weeks. After that it can be ad-hoc.

A: Yeah. Oh I will just go back and read that thing.

P: Yeah. That’s right.

A: That’s really good. Thank you. Last thing. We are trying to work out names. And naming things and marketing is really tricky. So I would love for you would – feel free to have a look at these and tell me which ones catch your eye. So if this was a marketing kind of poster somewhere and you were thinking about getting more active, which one grabs you the most?

P: I’ve just done a “Breathing matters” Have you heard

A: No

P: That was very interesting and the lady that runs it, she has five sessions, and I was able to do four and the fifth one I just wasn’t able to. It just didn’t work out.

So that just hit me straight away. My movement matters. I would say that would be number one.

A: So feel free to tick, number etc

P: Reads out list.. Cancer active, no I don’t like that. A stronger me. I reckon that would be alright too. That (refering to option) could be alright but it is a long heading.

A: Thank you I appreciate it. Cool. That brings us to the end of the main interview setting.