Study 16: Interview Transcript

Interviewee: “A” Participant: “P”

Participant ID: 012 Transcriber : John Rand

A: Cool, for the first part pretty generally Ian, I was wondering if I could start with a bit of background information about yourself. If you could tell me a little bit about your history with being diagnosed with prostate cancer and any of the treatments that you have completed.

P: OK well I was diagnosed in mid 2009, at the time I was living in Alice Springs and things were a bit difficult for me because of the distance, where my urologist was in Adelaide. I had radical prostatectomy in November 2009 and since then I have had three subsequent operations or procedures to correct my incontinence problems

A: Oh wow

P: But initially I had a bladder neck incision because they thought there might have been some sort of a restriction there. Then I had the sling operation which was not successful, in fact I went backwards from the time I had the sling operation and then I finally had an artificial urinary sphincter procedure so in all it has been a reasonably drawn out journey, but since the operation my PSA has been negligible so fortunately the cancer did not escape the capsule. I guess the major thing is I have got erectile dysfunction because of er in fact my prostate was pretty large, my Urologist told me that it was the size of an apple and it was one of the largest that he had removed so obviously there was some damage done when the prostate was taken out.

A: Yes, thanks for that, I really appreciate you telling me that so far. I was wondering if you view your health any differently now compared to before you were diagnosed.

P: My health generally is pretty good, I have gained weight because I have not been able to exercise as much as I used to. I used to bike ride al lot and because of the sphincter that has been fitted and everything that has happened I cannot sit on a bike saddle anymore so I have not been able to ride as frequently as I was prior to the prostatectomy. I still try to keep active, I swim every morning.

A: You swim? Well cool!

P: Yes, laughs, I live in a retirement village and we have got a heated swimming pool here. I swim about 6 mornings a week when I am home.

A: May I ask what your swimming process is, do you swim certain number of laps?

P: I do some aerobic exercises as well as swimming I do laps of the pool, it is probably about a twenty-five metre pool. I do anything up to fifteen laps of that pool but not constantly I do a couple of laps and then do some running in the water and then a few other exercises that I have got, I will be in the pool for forty minutes and there is a hydrotherapy spa as well, I hop in that for about eight minutes and then do a couple of cool down laps and come home.

A: May ask how you came up with the routine?

P: Oh, self-managed, self-thought out.

A: So decided to integrate those aerobic training stuff into the laps?

P: Well, not that I am a good swimmer but I have been around swimming for most of my life well most of my children’s life. One is fifty and the other is 47 and they were both good swimmers as my late wife was an excellent swimmer. My wife could swim fifty laps of an Olympic size pool every day. She was a very good swimmer, not a competitive swimmer but an endurance type swimmer.

A: Yes, that is a really good…, my goodness

P: I suppose, getting back to the health question, that is the only effect the operation has had on me. I have been unable to ride a bike and perhaps jog but I do not walk as far as I used to. I have had a pinched nerve in my back and that has sort of affected my walking a little bit but that had nothing to do with the prostate operation.

A: Yes, I was going to say, are there other things, because obviously you mention the incontinence and that would be quite tricky to be physically active I can imagine.

P: I have still got slight incontinence but not any-where near as much as it was after the operation.

A: Yes you mentioned your back and incontinence, do you think there may be other things that may inhibit at times.

P: I have had a busy life over the last five or six years with PCFA.

A: So you are heavily involved in it from the sound of it.

P: Yeah look, I have been on the National Board and until last Friday I chair a National committee. I have retired from my involvement with PCFA from last Friday.

A: It sound as though you have done lovely job committing to that so congratulations on your retirement.

P: Thank you very much (laughter)

A: So when some-one mentions exercise what is your first reaction?

P: Could you repeat that

A: When some-one mentions the word exercise what tends to be your first reaction?

P: I encourage people to be physically active, I have been physically active all of my life and I think that it has got a hell of a lot of health benefits. If you get away from a potato couch syndrome.

A: Absolutely

P: Physical activity does not scare me.

A: Are you doing any weights or…

P: Not really, I used to do gym work pre operation but I do not do weights now. We have got a small gym here with some very good equipment, I should try it to see whether it does affect me or not but I am quite happy with the swimming at the moment.

A: I love swimming too so I can very much relate to that, I really enjoy it. So how did you get into the swimming? You were mentioning that your late wife was into it, was that how you got into the process of swimming?

P: Not really, I did not get into the swimming much until we moved into the village.

A: Ah! So the access is easier

P: The access is easier, it takes me two minutes to walk to the pool and it is available eighteen hours a day. From six am until twelve pm so the access and the convenience is the reason that encouraged me to start swimming and I knew that I had to do something as I was not bike riding or running or walking.

A: So you….had to find an alternative that really works for you. That is really cool.

P: Well it has worked for me in one sense but it has not in the other because I have put on a few kilos in weight which I would like to get off. I am about five or six kilos above my ideal weight so I would like to get that off. That is probably the lifestyle that I have been leading for the last five years or so. Going out to dinners and lunches and things like that.

A: Yeah, can you tell me a bit about what sort of things tend to help you increase your activity levels, if you think of a facilitator as it were? You mention access that seems to be a big thing.

P: Just self-motivation I think, and the desire to keep healthy and live a long life.

A: Yeah, do you have a sense of what the guidelines are for physical activity for some-one in your age or health condition?

P: Not really, I could probably get some-thing from Sue C… she leads the exercise group at the health centre but I have not bothered about it because in the time that I have re-located to Adelaide I have not been able to commit to an exercise regime as such, a program.

A: Have you done a physical activity program before?

P: Well many years ago when I was pretty active in sport.

A: Was it a structured program? Or was it coach based?

P: Coach based, you would do what the coach told you to do back in my day in sport you did not have to have a certificate. You know a level four certificate in sports administration or something or sports physiology or anything like that not like it is today Amy.

A: Yeah I agree, in terms of knowledge about exercise have there been any people or resources that have been particularly helpful for you?

P: Not that I can give you any definitive answer on that.

A: That is alright.

P: I read some books but I would not be able to tell you who the authors of the books are

A: That’s all right, We will keep moving on and I know you are busy and it is late at night.

P: Mens health magazines, I used to read those religiously but I have not even bought one for a few years now.

A: Umm you mention Sue Tulloch so is having some-one with a professional background who is face to face useful for that kind of information then?

A: Oh Cool, well I will keep moving us on, so we are up to part three already. So many of my questions relate to my PHD as I mentioned to you a couple of weeks back. So the website that we are looking at designing will cover information about what exercises are recommended and demonstrations about how to do certain activities and how to build up your toolkit as it were and it will have the ability to track your progress over time and give feedback on that progress. So first we are going to ask you a couple of questions about your use of the internet at the moment and then I will ask you some thoughts on our research. Can you tell me a little bit about how you are using the internet at the moment.

P: Err the daily use or…

A: Yes the daily

P: Well mainly for emails I guess. And I do a fair bit of searching Generally do all my airline bookings and accommodation on the internet, I guess in short if I did not have a computer I would be lost. I keep my tablet and my phone to be able to get my emails. I guess I use the internet pretty extensively.

A: Yes definitely it sounds like it, do you have any sites that you like to visit because they are very informative or they have a good way of presenting information when you are looking at stuff.

P: Not in particular, I use uncle Google a lot but none in particular, if I have not got a website and I want to know something I will go to google and generally I can find it.

A: When you are on a website, not the search engine but a website are there particular ways that you like the information to be presented to you, do you have a preference for audio or video or text.

P: Oh well mainly text I do watch some videos but not many, it is mainly text

A: For the program that we are thinking about making we would probably be having a look at a length of about eight to ten weeks. Do you think that’s an appropriate length for such a program online

P: How many times per week?

A: Well we are working it out, my next question was going to say do you think that a weekly or fortnightly program would be appropriate.

P: I think a weekly log in, talking personally I think I could commit to a weekly login, as against a daily login. I think if it went to fortnightly you would lose not so much interest, you would lose concentration.

A: Yeah maybe it is not frequent enough to keep it going. Yes that is a really good point. I will introduce you to our two kind of different research ideas and then I will tell you our first one and get your ideas and then I will tell you our second idea and get your thoughts on that and if you could tell me which one you prefer that would be great. So our first idea is a program that is designed to give ongoing advice so you would login and you would type in some information related to physical activity so it might ask you how many minutes of lets say swimming how many minutes of swimming you have done and then it might compare it to the guidelines or it might compare it to the previous week or something and it will give you feedback dependant on what has been put in then of course each week would cover a different topic as well in addition to the feedback and it would go from topic A to topic B to topic C and it would unlock each week very logical. Would that be something that potentially you would be interested in?

P: That sounds good to me yeah.

A: Yeah cool, the second idea is very very much similar, it still has the same ability to log on and access the information and provide tailored feedback as you go, the only difference is that the topics will be available at the beginning completely unlocked and allows the user to navigate through the information themselves and access the information whenever you want. It would still have the same amount of information say eight to twelve week’s worth but it would give you a bit more choice about when and where. What do you think about the pros and cons about giving the information in this way and is that something you would be interested in?

P: Yeah that is probably better than the first option, you know, controlling your own destiny virtually. I think that both options are good but I think the second one, in my view, and it would suit my situation better I think, you could jump from one to another.

A: Yeah cool, well thank you for that thought. So, this is the last question of the interview section. Naming, what’s in a name. It is hard to pick a name of a program and have it sound approachable but not lame but it still explains what it is trying to do, so I was wondering, so feel free if you come up with any ideas later down the track, please feel free to email me I am very very open to ideas at this point. So I am going to say a name and if you could give me your immediate reaction that is great. So my movement matters,

P: Right right

A: So the next one would be Prostate cancer physical activity.com like it would be pretty obvious. i-strengthen?

P: Say that one again

A: You know like the lower case i in i-phone.

P: Yes yes

A: Ex-Med is another idea. Exercise Medicine ExMed

P: Yep

A: Or My Fit or Cancer Fit something like that.

P: Right, yes

A: Any of those grabbing you at all, or not yet?

P: Yes, it is aimed at prostate cancer

A: Yes

P: I think you would have to put prostate cancer in there somewhere.

A: So something like health and well-being

P: In prostate cancer or something. Yes something like that yes. And you could probably put i-view or some technical jargon or something in there. But if you want to get the attention of men over forty you would need to have prostate cancer in there.

A: Yeah make it really obvious.

P: Or prostate at least.

A: Yes thank you for that. That is a really good point.

P: If I was given a list like what you have just read out, I probably would not go to.. well there might be one or something. The ExMed that might attract me but certainly.

A: It needs to be a bit more specific

P: I say this because before I was diagnosed I did not know what the prostate was.

A: Before I started my PhD I didn’t really know what it did

P: I think you’ll find that men are becoming more aware, but there is still a long way to go getting men familiar with prostate cancer and what the prostate role is in a man’s anatomy. So to get attention, you would at least need the word prostate in it.

A: Thank you. That brings us to the end of the interview.