Study 2: Interview Transcript

Interviewee: “A” Participant: “P”

Participant ID: 06 Date of Interview: 31st 08 2017

A: So the first part is pretty general, um I’d like to start if you’re up for it to tell me a little bit about yourself in terms of your history with being diagnosed with prostate cancer and any treatments you’ve had so far?

P: Yes I was diagnosed with um, well first of all my PSA was, my cancer was first of all was diagnosed in 2006.

A: Ok

P: But before, but before then my psa reading er was 5 then it went to 11, and then er, the er specialist that I had – and I blame him for the type of cancer that I have, because he never showed any concern.

A: Mmmm

P: And and if if the psa reading is going up there must be a reason for it. And he said ‘oh well you know well if its something well we’ll get to it’ and this and that – um and then he said well this this must have been in June that I saw him- he said well I’ll see you again in November. And by the way and then and then I’d had two biopsy. Sorry two sessions of biopsies and then each biopsies, and it showed clear. I had no er, um, no er, whats the word I’m looking for? No er- symptoms at all, you know

A: Yeah

P: I could pass urine fine, no blood. Nothing nothing whats so ever. And so he said, he said see you in November, and I thought, we’ll we thought, my wife and I. You know the more you ignore something the worse it will get. I kept my November appointment. *Coughs.* Then ah, er I think er, April May something like that, came or March came. Can’t remember exactly. I had my psa reading and it went to 35

A: Oh

P: Yeah, it really shot up

A: Yeah

P: so I went in again, so I had another blood test not a few days after it went to 35, oh well we gotta have a scan and this and that. And of course by then the problem was that the cancer – it had escaped from the prostate to the to the lymph area

A: yeah

P: You see it was *cough* so I blame him for because, you know if the psa- see what I’ve learnt today is if the psa moves there’s a reason

A: Yeah

P: But he never showed any concern what so ever, you see in my experience I’d say look, lets look at it definitely every 3 months with blood tests and see how it moves and so one. So that’s what I’ve learnt from my own experience. As I say I blame him in in in my whatever, um that he never showed any concern

A: Yeah

P: Yeah and he should have. So then of course yes, I had er, I can’t remember if I the the CT scan er er or a certain other- but the cancer was there and it had spread

A: Yeah

P: And then I I er went to the this chap doctor that I had. The specialist I had referred me to to er, *name of practitioner*. Anyway, so I went to see him and er he really laid the law down. He um, can’t finished, sorry. *Inaudible* For me my wife and I - He virtually built a coffin for me then and there.

A: Mmmm

P: So then my way, cos my next door neighbour had er um um, was also treated with cancer. And he said oh look forget *name of practitioner-* go to *name of practitioner* he supposed to be the top guy or whatever. And because my wide, you see has intuition, she thought that something could be wrong, but she actually made and appointment with *name of practitioner* for me in September. But then my next door neighbour, --- anyway the day she rang me and said come and see my Thursday. *Inaudible* Well *name of practitioner* was totally different. And yes you’ve got this and that and er and whatever but we can treat it. We can do this, do that. Straight away he put me on to xyablex or Zoladex

. Or I may have the last one wrong, the last one xyabex is the one you put in your tummy through tablets.

A: Is that is that is that a hormone treatment

P: Yes, and xyablex or Zoladex. Don’t hold me to the half one but its in tablet form. But but he said give this for a couple of months, if the psa- I also had radio therapy. And you have to be set up and looked at. Well I said well look, by then might have been June July, I said looked I’m booked to go to Italy in September

A: Oh Italy

P: Should I put it off, he said no no, we’ll do all the treatment the um, the radio therapy when you come back. So you know when I did come back I had radiotherapy and it it was yep. Nothing’s a good experience. I was going to say it’s a good experience but er. But um to me radio therapy is er, it did not it did not harm me like you hear most people say- you know, they gotta a , they can’t move from home, they’ve got to be close to a toilet

A: mmm

P: I had nothing like that, cos I had my radio therapy at 9 oclock in the morning. By 9:30 I’d be at work. Work and play sport. It didn’t bother me at all. You know it was, I used to paly golf and I still go to golf when the the time er when er erm when time- It didn’t effect me at all -0 the radio therapy. And I thank God for that and I gotta say he got me through God. So I’m sure my belief has helped me to deal with the harmful bits that most people get with radio therapy

A: Yeah

P: I had had none of that. And er, so er after the radio therapy, and the ere r cylodex and *inaudible* I- had to be on that for 12 months and then see see if through for er- Around November, yeah that’s right, November and the first days of deember I had the radio therapy and then my psa went to 0.4 or something.

A: Oh good heavens

P: Really nothing you know, and er, since then I um. You know have *name of practitioner* every 6 mo- I mean every 3 months I have a psa reading. When – I think- *name of practitioner*’s opinion- if it gets to 1 or before it gets to 1- he would like to to have a cylodex again treatment which is the hormone treatment. And er since then 2006, I think I’ve had it twice, 6 month course. Cos you see, from 0, sorry from 0.4 it would go to 0.5 or 0.6 whatever whatever. It gets close to one, and then *name of practitioner* says oh well lets hit it again. I’m sure that I’ve had it twice – 6 months treatment

A: mmm

P: And now, I’ve um, my psa –I had my psa done yesterday but I don’t know the result, but the last one was 0.05 I think or 6. And it went to point 0.5, it went down a fraction. So -So far so good. And I think that *name of practitioner* said that its about 2 years since I’ve had hormone treatment.

A: Oh that’s that’s yeah-

P: I have to go see him on Monday, to see what my result is.

A: Yeah

P: But so far so good. I er, I’m very active, I gave up golf because I took up bike riding, course when you take up bike riding- I leave at 8 o’clock in the morning and on a Saturday come home at 1 and all of a sudden its 4 o’clock- so I can’t say to my wife I’ll go to golf *soft laugh* tomorrow

A: *soft laugh*

P: - so so no golf. So I’ve been riding now a push bike for nearly 10 years

A: Yeah

P: And er, and its my my way of keeping fit cos you know with the hormone treatment, you put weight on, muscle wasting- what else, lots of symptoms. And as you know, I suppose you know, that that the the the best therapy for this - keep active. You have to walk. Bike riding, good food and so on and that’s what we’ve been doing.

A: Yeah, I was going to say- May I ask where you learnt all that information? When you were talking good food and exercise in terms of going um, when you’re doing that treatment- who was the one who told you all that?

P: With dietary- I mean my wife has been very astute in er, you know- have salads, fish chicken or whatever, we’ve always been that way inclined. Having good food- I mean good nutritious food, not. We don’t have rubbish for dinner at all. Too many you know and then er-

A: would you say----

P: ----So and the exercise. I don’t know where I picked it up from. I think my wife has done a lot of research that exercise is an important key factor.

A: Absolutely, so where you active when you were younger as well?

P: Er no, I worked a lot. I had had I had my own business for 33 years, and I was very active in my work- um, as I was saying my only other exercise before bike riding was golf.

A: So so when someone mentions the word -

P: *soft laugh*

A: -physical activity or exercise whats your first reaction?

P: well I know er, cos cos um, I um, I’m nearly 180 or so, um, 6 foot tall right? And I weigh 95 kilos, and you know, I do have a bit of a tummy which er probably caused from hormone treatment. And I always tried to keep the weight down, so then- that’s how I’ve started being more active

A: Yeah yeah

P: In my lifestyle

A: um, would you say that you’re the way that you view your health is different now compared to before the diagnosis?

P: Er, probably- only more active in in exercising than I was. But in my health wise, I was always- it was always a keen factor. With my family, we’ve always had diabetes and and heart problem within my family. So I’ve been very conscious, of each year- have a full blood test, check for diabetes, check for whatever else. All that, always very aware, always very aware of my you know my health.

A: Yeah, cool. Well thank you for those responses so far that’s been really really good. Um, do you- so you mentioned how being on hormone treatment you learn about the muscle wasting and stuff- did they mention strength training at all?

P: No, no that’s something we’ve learnt ourselves- from watching TV or whatever. I saw somewhere on Facebook I think it was- this person from – with a research also- from University in Sydney and he did this- a real physical strength exercising and er, gym work. And its helped him um, but I I used to do gym work. Erm, but my bike riding, we do 60 70 kms on a ride

A: Wow

P: Plus I participate in the tour down under which is 155kms, 160

A:Wow

P: So I do a lot of- particularly in November, onwards I will probably ride 3 rides a week to get fit enough for the bit ride. November- before that here is ride like crazy which is 120. And the tour down under which is always 140 150 160 kms. So you know. So you have to keep moving.

A: Oh wow. Um in terms of

P: Sorry, oh sorry. I stopped cos er one year I was doing bike riding and then gym work on a particular day and I thought at the time that er- my – for me it’s a problem for hill climbing. For me I need stronger legs, what ever what ever, its not giving me the experience whatever so I stopped. But I’ve been meaning to get back to it- see if I ride twice a week and go to the gym- keeping in mind this research that this fellow chap in Perth, through the University on Sydney that they said that the physical gym exercise is very good for you- So I was going to take up gym once a week and ride twice. And that’s physical gym work on one a week but I haven’t started it yet.

A: Yeah so in terms, of It terms you’re really motiving with the cycling which is wonderful to hear. Can you tell me a little bit a out what things might stop you from doing physical activity, some sort of barrier perhaps?

P: Sorry I didn’t quite understand the questions- I didn’t quite understand the question?

A: That’s aright? Can you tell me a little bit about what things might stop you from doing activity regularly?

P: Stop me what previously?

A: I mean in general- if um, for example if you found that you were really lethargic after treatment or any other medical conditions or even the weather.

P: No no, I’ve never er, I’ve never um, its its it’s the – my prostate cancer has never held me back

A: Yeah

P: Whatever I used to do at work, you know work 6-12 hours or whatever, 6-7 days, well not 7 days. But 6 days a week- it never held me back.

A: Mmmm

P: I always kept kept moving. I just do what I had to do. I never felt lethargic or I “oh I don’t think I’d be able to do this” or whatever. You know, I’ve always had the motivation to just get going.

A: Yeah, is that – are you quite a strong[ly] motivated person do you think?

P: I think I’m a strong minded, yes I think so yes

A: Yeah yeah

P: I always look things in a positive way instead of a negative way

A: Yeah yeah I think that helps

P: Be right tomorrow

A: Yeah, in terms of like- back to the question about physical activity, um so I asked about barriers now I was wondering if you could think off the top of your head what might help you to increase your levels of physical acti---

P: --- Now…Now?

A: Yes, as of now yeah

P: Um, well I do a lot of walking

A: Yeah

P: Um, apart from riding, I do physical activity- like this week I had a hard week- doing gardening, shopping, pruning- whatever. I worked like a dog for 3 days so you know, you know. Nothing- nothing seems to be too greater effort. I just get in there and do it.

A: Yeah you just get on with it

P: Yeah one of these, I think the quicker I can do it the quicker I can stop *soft laugh*

A: Yeah *soft laugh* that’s a good way of think about it. Um, so moving on to part 2- um I was wondering if you had a sense of what the guidelines are for physical activity for someone of your health or condition or age at all?

P: Yes-

A: Yeah?

P: oh sorry, I didn’t quite understand- you mean to have a guide?

A: Oh no , um no, so it turns how that there actually are health guidelines for physical activity for men with prostate cancer- but I’m wondering if someone has every mentioned it to you?

P: No, its always been- well for myself- see I’ve done little research for myself but my wife has- she’s been involved in a lot of reading- she was in nursing herself so- you know- so she’s always done a lot of research and er- good food. Er exercise, um, keep active- it all comes from reading that she’s done.

A: Yeah cool

P: Cos I’m lazy in that way *soft laugh*

A: Well *soft laugh* it sounds like you have a very supportive partner so that’s really lovely

P: Yes yes --- she’s yeah

A: So we’ll just move on to part 3. So obviously these questions lead me to what I’m already doing at the moment.

P: Yes

A: I’m in my 2nd year of my PhD and of course we’re designing an online resource for men who want to be a bit more active and it sounds like you’re a very active person--

P:--- Yes

A:--- so perhaps you can give me some tips. The website will be a place that you log in and um, tell- the computer program will ask how much information- er, how much activity you’ve done in the week. Um, and then it will say “oh you know, you’ve actually done a good job this week but you’ve missed out on your resistance training can we work towards that”? It will be quite a tailored approach. Before I get into that too much, I’d like to ask you some questions on the internet and then some questions on on my research.

P: By the way, I have a fit bit

A: You have a fit bit?

P: Oh yes I’ve done 8000 steps today, and it tells me how much sleep I’ve had over night and so on. See my goal is to get down to 85 kilograms- when I’ve started it was 95- it doesn’t come very very fast-

A: Its its all sustainable change, its all about sustainable change so

P: Yeah yeah s

A: May I ask what you like about the fit bit?

P: Oh just, oh I think it inspires when you look at it-oh I’ve done 6, id better keep going I’ll do 8 you know.

A: Mmm

P: It is another form of getting getting a move on.

A: Yeah I think its um- what is it- it quantifies it for you. You know like in your head you’re like oh yeah I’m active, but when you see the numbers there you know.

P: Oh yes yes, particularly of the last few days cos I’ve been working- I’ve done 12 thousand 13 thousand- you know you’re moving around all the time. And er working and bloody hell I’ve done that much. *Soft laugh*

 A: So if you have a fit bit, I’m imagining you use the internet quite a bit.

P: Oh yeah, my wife always says get off the computer’
A: Yeah. May I ask what sort of websites that you like to use a lot- you mentioned Facebook.

P: I’m I’m a manic Facebook- keeping I touch with friends in Australia and across the world, and yeah. With the internet, I mean Ive got- I mean what works, I mean you’ve got- *inaudible* I can’t really pin point in particular

A: That’s alight

P: If I have to look up some particular thing and what ever.

A: Yeah, so if there was a program online would you feel confident at using without too much trouble?

P: Probably not, cos if if er, if I had to learn- if I had to start again- what do I do now?

A: Mmm

P: then I probably would but now- you know I –personally I probably wouldn’t because as I say I gotta keep riding, I gotta keep moving- I gotta eat good food and so on so probably not.

A: mmm

P: I don’t know.

A: That’s alight, its all good- we’ll move on.

P: May be if it was a different opinion—if I want to change my mind then I might look at it then I will want to see what else is new. Yeah that’s another thing, if there is something new- see I er um, I like through *name* we are both involved with lectures and stuff with men’s health.

A: Yeah

P: You know the Freemasons foundation centre for men’s health-

A: Yep that’s my group

P: I think I’ve cut the name in half by the way *soft laugh*

A: Yeah it’s a bit of a mouth full

P: That’s right, anyway if you here something new, I’m always interested to hear about something new. By the way- you do know a thing- I I why would it- why would I look at a website- maybe not. I always seem to be too busy.

A: Yeah

P: I’m very highly involved in freemasonry and I’m secretary of a particular lodge and theres always too many things through that- sometimes I get an information- er, through *name* will send me stuff about whatever. And a lot of really- I haven’t got time for that now- so I delete it

A: Yeah yeah

P: Yeah if it’s the same if I’m not walking or whatever, I’ll do that on the computer- I have to do things I have to play around and look at things. I have to do do things.

A: Yeah yeah, is that why the fitbits useful cos it doesn’t require too much time?

P: Exactly exactly, if you wanna look at the results, how much did I sleep last time? If you don’t look at it it doesn’t matter.

A: Do you think you’d prefer to have the information as audio, or visual or as text. Or perhaps a combination

P: oh look its something to be read like an article, then I’ll read it. Cos cos if there is interest there I’ll read it- you know the the other day I received 3 resumes and something- you know they were 2 page A 4s- two A4 pages, well I read every word. Cos I wanted to now what was what- so I read that you know.

A: Yeah yeah, um so hypothetically, if I wanted a general opinion

P: yep

A: Do you think 8- do you think if the program went for 8 weeks do you think thats an ok length?

P: 8 week of learning what to do with yourself?

A: yeah 8 weeks of a physical activity program- what are your throughts on that?

P: Yeah its probably all right, lets illustrate. If there is a new way of exercising because part of- there is some sort of exercises, some gym does it- some gym- gyms does this particular exercise, particularly for prostate cancer people.

A: yeah

P: So they, well if something comes up then I will look at it yes.

A: And um hypothetically do you think fortnightly or weekly is a better frequency for contact?

P: Um, I think weekly.

A: Um so this is the last section. I’ll introduce to you our two reseach ideas. So the firs one is, if you can imagine- you log on and you give your information about how much you may have done in terms of activity that week and it will give you some advice. But there will also be some topics covered. So once a week it will open up a new topic, and it might be on appropriate goal setting, or maybe it will be on working through treatment side effects and exercise. I know that’s not the case with you, but I’m giving you an example. And it would be very logical, going from A to B to C, and it unlocks each week. Um, would that be something that interesting to you?

P: I think it would be interesting- I’d find it interesting if I’d look. You’re talking about mainly exercise aren’t you?

A: Yes,

P: Progression and exercise?

A: Yes yes

P: Yes I mean yes,

A: It would be similar to fit bit but for prostrate cancer specially

P: yes yes, well if I see something new then I would want to progress with it- you’d look at it read about it, watch a video whatever- then I would follow and push. If you tart something you want to progress and you look forward to see what else is new next week or whatever you know.

A: Yeah yeah. So that’s the first idea, so the 2nd idea is pretty much the same with the difference being- you see we are experimenting here, so the difference would be instead of unlocking over time- you still have the ability to get tailored feedback during the period, but you have the ability to look at the information- all the different modules at the same time and you can pick and choose what you read. Um, what do you think are the pros and cons of giving the program in this way?

P: Well probably that’s a good idea in a sense. Cos something I would know and think this is bloody boring- and you’d skip that and you’d find something that would hold you and have a look at. And you’d say from next week of 10 things that are going to occur, then I’d pick and chose which ones I would enjoy more. Cos anything you do, exercise or work or whatever, you know, you have to enjoy what you’re doing.

A: Yeah

P: If I could pick and choose whichever, I think I’d enjoy that one better, or if there was a choice I’d do this one not the other one. So I think yes, I think adding a choice to see what you could do--- er and something’s wills uit some and not others.

A: Yeah yeah, cool. Alright so this is the last question of the last section. We need some help with marketing. The program name needs to be appropriate and its not too wishy washy but it also grabs your attention. As marketing can be quite trick.

P: oh yes

A: So we have some names for the potential program and if you could let me know what you think, like oh I like that or no I don’t like that- Think of that as a flyer, and if you saw the name on the flyer that you might click it.

P: Yes, so if I liked the program name I would look into it

A: Yep. So the I’ll read a list of names and get your thoughts on them. My movement matters, er tailored to me, cancer fit, prostate cancer physical online, I strengthen, exercise medicine, or prostate cancer health and fitness online- those are the ones we

P: So I think the best ones to me would be the last one or the first one.

A: So the first one was my movment matters

P: so what what was that one

A: my movmemy matters was the frist one

P: yes my movmemt matters was a good one. And the last one

A: or prostate cancer health and fitness online

P: Yeah

A: Cool, alright well that brings us to the end of the interestview section. To complete our research we would like your opinion on 4 physical activity sections we have taken from other cancer websites. They are about a paragraph long and we can either mail or or email that to you. Once that’s completed I can post the $25 coles/myer gift voucher to thank you for your time. Would like email or the post for the survey.

P: Oh email no problem, yes email would be fine.

A: And oh, I’ve got your email. And could I grab your postal address so I can send you the $25 gift voucher.

P: Look save the money, I’d really prefer that if I could give something- I’m glad. I don’t need any reward.

A: Awww, are you sure?

P: Yes yes,

A: Ok

P: Give it to someone who would like it- to me, if I have contributed towards good health then I’m glad, I’ve done my bit

A: Well, *name* I really appreciate it, your time, thank you so so much for your willingness to participant. I’ll send you that email to you and if you could complete it within the next week that would be wonderful.

P: Yep.. And good good luck with your research.

A: Thank you very much, I really really appreciate your time.

P: Yep, well

A: Well thank you, and have a great rest of the night

P: yep

A: Bye