Study 2: Interview Transcript

Interviewee: “A” Participant: “P”

Participant ID: 001 Transcriber: Amy F

A: Just to get a bit of a general background I’d just like to ask if you could tell me a little bit about your, your history history, um, with being diagnosed with prostate cancer?

P: Ok. In 2004 I had a medical to join the International Energy Atomic Agency in Vienna- and my GP was filling in the form and said “there’s no space for PSA, but you’ve had it done, so I’ll just write it on the form.”

A: ok

P: When I arrived in Vienna, I was fairly elderly as you can work out

A: *laughs gently*

P: You have to have a medical, every twelve months, and I said fine, I do it anyway

A: Mmmm

P: I went to the medical centre and um, I said “by the way, this that and the other”. And they said “yeah, that’s cool, come back next year.” And then I remembered that one of the last things that the GP said to me was “you make sure you get don’t go more than two years without this being done again.” And I said “ok”-

A:- Mmm

P: So the next year, I went out, obviously this is 2006. I went in. Had my medical. And I said “oh, PSA.” And they said “Oh we don’t do that.”

A: oh?

P: Chief medical officer doesn’t believe in it

A: oh

P: and that’s fine, my GP does, it was a bit of a he says, she says- so I said “whats the big problem?” And they said “whose going to pay?” And I said “I’ll bloody pay, how much is it?” Its 13 euros 20.

A: Oh dear

P: So they gave me a bill for 13 euros 20. And I went back and saw the GP, who at that time had become a young attractive Italian lady. And I said “So whats the go?” and she said “Mmmm…I’ll show you this list-of people, who I think one of whom you should pick to go and see.”

A: Mmmm

P: And I said “why?” And she said “because you’re PSA-”, which was what ever the number was, 1 or 2, “is now 4 point something.”

A: Yeah

P: And I saw “oh, what does that mean?” And she said “that’s why you need to go and talk to someone. So I chose Professor Doctor Emeritus (*practitioners first name*) some body or rather, purely picked on the grounds that he had the longest title and he was an American professor at the medical university.

A: Ok

P: And I went to- I mean what else do you do? I was in a German speaking country (*interviews name),* I don’t speak German like your dad.

A: Yeah yeah

P: So- off I went. And he said “ah well, you, you know, pee in a cup and we’ll do some blood tests” and- in the mean time its probably a very common infection, I give you an antibiotic- you take it for 30days, come back.

A: Mmm

P: So I took the antibiotic and went back and he said “ah now we gotta do the tests again”- and you come and see me if- in two week. So I went to see in two weeks, and he said “mmm- its gone from 4.1 or 4.1, or something- So that’s not good.” And I said “how not good” and he said “well, you’re gonna have to have a biopsy.”

A: Mmm

P: So I said “ok”- So I went off and he did the biopsy, and that was an interesting experience…

A: Mmm, uncomfortable from what I’ve heard”

P: And in two weeks, and I went to see to him in two weeks- and now it was the lead up to Christmas.

A: Mmm

P: So I said “ok”, and “how are you going Doctor Professor Engeineree Emeritus?” and he said “what are you doing on the 1st of January?”- and I said “really that bad?” – “oh yes really that bad”.

A: Oh dear

P: But I had no symptoms, no problems, none of the things one reads about and hears about. And he said “No- but I can tell you—“ , now you, now I can’t remember the detail now but it was somebody or rather’s damn number.

A: Mmmm

P: Seven means you’re dead

A: Oh

P: Effectively

A: Yeah

P: Um, one or two-we home and don’t worry about it. Anyway, mine number was something like 5, and 5 outta 7’s really not good.

A: Yeah

P: And I said “ But I still don’t have any pain or problems or anything.” And he said “Well no, but you’ve got cancer and its running riot.”
A: Yeah

P: So I said “ok”, and he said “but tell you what, 1st of January isn’t a real good day” and I said “probably not, I’ve…” . So I said for mid to late January.

A: Mmmm

P: And I said “so whats the go?” and he said “oh look, its key hole surgery- but it has to be a radical prost, prosta acetomy (*stumbles over word).*

A: Prostatectomy yeah

P: Whatever the word is. And er, fortunately the guy spoken relatively good English- cos otherwise I’d have been completely stuffed.

A: Mmm

P: Um, and they said “So- you could look this up on Google here, you could do this here but to be honest but its not going to be good but you will be alive.”

A: Mmmmm

P: And I thought well- that’s fair enough. So, I went outside the street and rang a lady friend in England and said “I’m, I’ll be over for Christmas except that I couldn’t stay for Christmas itself but I had to be back for it and that will be it girl.

A: MM

P: So that was that

A: Yeah

P: So yeah, I went to the UK, um, came back and checked into hospital. Um, had the operation, woke up in ICU which is the most *horrendous* experience.

A*:* Awww

P: Well my nurse was Slovakian -was absolute superb nurse of the ICU. Well the ICU is all bells and lights and whistles and- there’s no way that you can get any sleep.

A: Yeah

P: I forget you got tubes things and you’re all wired up – but- there is just so much going on. Anyway the professor doctor interview came round and said “yep we took a few lymph nodes and basically we got it.”

A: Wow (8.20)

P: So I said “Really?”- And he said “Yep. It must have come on really fast and really aggressive, but there is no evidence that its ever spread

A: Ahh

P: So I went back to bed sharing a room with an elderly gentleman- ha, I say elderly gentleman...”

A: *soft laugh*

P: Who didn’t get it- he’s had a bit more of a problem as me, and didn’t have quite as good surgical outcome as me.

A: Mmm

P: But he was a lovely man and we spoke a common language, and we watched Wimbledon - not Wimbledon – something- we watched open tennis from Australia all night on the television.
A: Wow

P: And sort of dosed during the day and watched something else in German, during the day, it was another sport, skiing probably

A: Yeah

P: Anyway after a week or so, they threw me out and um, and my lady friend came over from the UK to take me home from hospital- take me back to my flat, and look after me for a week.

A: Mmmhmm

P: Um,

A: Yeah

P: It was a very celibate week as you might imagine.

A: Yeah it would have been quite a stressful time I imagine,

P: and then it would have been another week and now we are around about the middle of February because my first public outing was to go to the IAEA ball- very very gingerly.

A: Mmmmm

P: Um, and one of my sisters came over from the UK with her husband and a load of other mates so we had a nice time---

A: Mmmmmm
P: Ah, except I was on my own.

A: Mmmm

P: And um, I then went back to see the doc, and he said “well,” –um, gave me some injections, and said “well there you go, its not going to work ever again.”

A: Mmmm

P: So, I said “really”, and he said “well I could give you something you could inject yourself, or you have siarlets, could have take half a tablet every day.”

A: Mmmmm

P: Ahh, but you know its not looking good. And the answer is, he was quite right.

A: Yeah (10.20)

P: So I decide that um, that sticking myself with a needle really wasn’t worth it, um, so I haven’t bothered since.

A: Yeah, in in in terms of your health, do you think you view your health differently – um sort of now compared before you were diagnosed?

P: Um, its interesting (*interviewers name*) I guess I’m probably a little bit more health conscious.

A: Mmmm

P: That doesn’t meant to say that I do a great deal more about it. Um, ---um---

A: So have you changed anything about, sort of, about the way that you live?

P: Oh I sort of try to keep a better eye on my weight; I’ve certainly lost weight.

A: Mmmmm

P: I’m sitting here with a camembert cheese and a bottle of red wine, but um, but I also take statins which has a bit of a neutralising effect. My GP is fairly happy with the way I live. And I see him every every 6 months, and do the PSA periodically.

A: Mmmmm

P: Absolutely no problems there,

A: Yeah

P: Um, I guess- one of the things I feel is that um- been there-done that- beaten it

A: Mmmm, yeah

P: Which kinda gives me a slightly different outlook on life.

A: I was actually going to ask, yeah if you see life differently or if you’re values have, have changed at all?

P: Um, I probably don’t get as up tight about stuff as I used too.

A: Mmmm

P: Um, but that may be just be aging and mellowing anyway

A: *soft laugh*- or the red wine.

P: Yeah or the red wine,

A: *soft laugh*

P: But I mean certainly, um, you know, people come in an work – office staff of 20 odd now, and I really know you, I really think someone- Jesus have you not got a life. Cos you know, I mean I’ve had a sheltered liberty life, but you know, that’s just circumstances. That’s nothing to do with the cancer.

A: Mmmmm

P: Um, well I supported in one way it might be, cos I’ve- I don’t have a partner but then again, its just not often I miss a partner other than the lady in the UK

A: yeah

P: Yeah, she and I talked with regularity and I go across to see her 2-3 times a year

A: yeah

P: Um, but I mean certainly I do have an element in the been there beaten it

A: yeah

P: I had a sister who had some form of colon cancer

A: Yeah

P: Or rectal cancer, I think, and she beat it,

A: Yeah

P: She’s back to normal - more or less. And the bags gone and you know She and her husband came out here for God’s sake. They run around the word,.

A: Wow

P: My baby sister who is called (*name*), which is why I should have remembered your mothers name – um, and she has a form of MS which I think is absolutely ghastly.

A: Oh, no yeah, that is really really tough

P: You known, and (*UK Partner name)* and I have been through what we’ve been through but I reckon I got through really easy.

A: Mmmm

P: And I got through on my own, in Vienna with lots of Germans. (14:33)and it was all on the health insurance.

A: Mmmm

P: Well, 90% was on the health insurance it still cost me a few thousand euros, but it would have cost me a hella lot more if I hadn’t been insured

A; Yeah- Um so I don’t want to take too much of your time so I might move us on if that’s ok.

P: Nah na, plenty of time.

A: *soft laugh* oh well that’s encouraging

P: Well I certainly have plenty of time *soft laugh*

A: So the next section going to be a little bit, um, more about kinda of lifestyle and and your thoughts about physical activity. So when, when someone mentions the word “physical activity” or “exercise”- what’s your first reaction?

P: Yes. \*pause \*Must do more

A: soft laughs, yep- I can, I can understand that. Can you tell me a little bit about the challenges you find to be more physical active?

P: Ok- um, in Vienna, um, I used public transport- cos it was so great- I mean you must have been there.

A: mmm it was its fantastic.

P I was there 7 years, walking round the office keeps you fit, for Christ’s sake, I mean the UN complex goes on forever

A: yeah its flipping huge

P: I used walk to the bus and used get the bus, walk around the office, the Ubah, I lived on, or just off the ring strasse, I walked across the centre of Vienna without a moment’s thought

A: Mmmm

P: I used to play golf during summer, um, I was, I was quite a lot more active

A: yeah

P: Cos I, I had a year with um, another medical problem

A: Mmm

P: which kept me on and off crutches, which was er, intra-oscular odema in my right femur

A: Oh, that sounds painful.

P: Which was yeah, yeah it was, and it went a way and then the bloody thing came back which- and I played golf here with an orthopod, and I played gold in Vienna funny enough with en orthopod. And they aren’t supported to come back cos once its gone its gone, but it came back in the same bone but in the other process.

A: so-

P; anyway

P: yeah

A: Anyway, came back from Vienna to Darwin, public transports rubbish and its not a place that you walk to work especially during the wert seasons. Quite a car- I don’t do nearly enough- bought an exercise bike and er, subtle pressure from a dietician who was sent round by my GP.

A: Ahhh

P: Um- good move that- till she got pregnant

A: Ah.

P: But you know what I mean, I mean there was someone who was coming around every 6 weeks going ‘how are you going?’.

A: Mmm, so having someone was accountable---

P: You know, “you promised me a target, how are you doing?” . I tried going to a gym but everyone is about 12 years old and super fit , so forget that

A; I can, I can understand that.

P: I try to walk a bit, but its too hot and humid a lot of the time. I do gardening, I occasionally walk to the shops but most of the time I get in my car and go the supermarket

A: Mmm

P: Um, I do try and ride the static bike two or three times a week.

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

P: Oh God no

A: No, no worries

P: before I went away, I had a mate um, who I used to go to a gym and before work 2-3 mornings a week and we did the pump stuff

A: Mmmm

P: And that was quite amusing but I’m a lot older now and a lot more sensible. *laughs softly*

A*: laughs softly* understandable. So you mentioned that the the femur um, was a really massive barrier for you, um when it comes to activity, and you mentioned a few other things. Do you think that there is any part of the the treatment that has created barriers or something from the cancer itself

P: no

A: no?

P: I meant the oedema was in no way related to the prostate and we went through all that with the doctor and the orthopod, and with the professor

A: mm

P and they said no you’ve just been unlikely

A: Yeah have-

P: yeah I’ve gotten away with the prostate cancer I reckon I shouldn’t complain/

A: Are there, are there any other medical problems that that have become a bit of a barrier?

P: I guess, I’m 71 now,

A: Mmmm

P: and things are getting a bit tougher

Um, I’ve had a shoulder problem which I suspect may be coming back- and that’s a problem because my golf plumping orthopod is now retired, but um, when I first gott my shoulder problem, he said “oh pop in and see me” and he stuck a needle in me and that was the end of that

A: Mmm

P: Um, I just need to do more I think- and that will overcome that. I’ve also had um, oh- some problem with toes on my left foot are going numb.

A: Mmmm

P: Somebody stuck steroids or cortisone or something in there, I’ve got another toe that doesn’t hurt it-

A: mmm

P: I mean I’m 71 for God’s sake, I mean

A: yeah, yeah theres- er, its always tough – sort of you’re body’s not quite what it used to be at 50

P: Yeah, I mean the nature of my work, I used to be, or even at the agency, there was a fair bit of stairs and walking,

A: Mmmm

P: going on buses- all the rest of it. The big difference I guess is, you know, I mean I’m in an air-conditioned office, I don’t go on site anywhere near as much as I used to.

A: Mmmm

P: When I go down Sydney to visit, and old school chum who is a year older than me. Now (*name)* has always been super fit but I mean you now, we go somewhere and he runs up the stairs and I go I’ll catch up with you in a minute

A: Yeah. Um, so you mentioned that that the dietician checking up on you was quiet encouraging for you. Do you think um, Can you think—

P: Just just pride

A: Yeah yeah,

P: but it worked

A: yeah, I was- can you think of any other things off the top of your head that could potentially help um, you sort of improve physical active levels in your life.

P: Well activity I guess um, getting a partner who wanted to do not too much- um and sharing stuff- that would make a big difference. Being on your won its too easy to be lazy

A: Mmm, so sort of an accountability?

P: Absolutely

A: yeah yeah

P: um, um, I guess that’s part of it. The other thing is particularly here, one is not so inclined, given the climate, to rush around

A: mm

P: When I’m in Europe, I go to Vienna to go to the Christmas markets every where or maybe if I can persuade your dad to have a meeting.

A: *laughs*

*P:* I’ll happily start off just walking the Ubahn and getting on and off the bus- by the end of the week I’m feeling quite a bit different.,

A: Mmmm

P: yeah that’s crazy- a week can’t make too much difference for Christ’s sake

A: hyeah I mean sometimes it can- you never know. So just, in terms of um, what the guidelines are do you have any sense of what the guide lines recommendations are for someone of your age or medical condition?

P: Um, I don’t believe I have, I well, I don’t think I have a condition, I think I just am a condition

A: haha yes,

P: more of state- um, but yeah. I think the dietician said look if you can get on the bike 2 thirty-minute sessions or 3 or 4, 4 or 5 lots of 15 minutes Monday-Friday that’s cool cos you’re a bit more active on weekends.

A: Mmm

P: Um, I would have loved to, to have gone back to golf, but golfing mate survivor died, moved on, or have problems which deter them playing now,

A: Yeah yeah

P: I’ve only played 2 or 3 times a year now

A: Mmmm-it does make it challenging when there is no-one to play with I can image

P: Mmmm. And yeah, and you known golf, um, I have been known, oh, have been known, you know, to go down to the gold course here in Darwin and um, and on a quiet morning, and er bash around on my own.

A: Mmmmm

P: but its becoming harder and harder to get enthusiastic about-

A: yeah—so I might us move on to- ah- telling you a little bit about my, my PhD project. So a lot of, as you kinda have figured out, a lot of the questions are about kinda about physical activity. So I’m in the 2nd year of my PhD and um, we are looking to design a program or an online resource, if you will- Um, for for men with a history of prostate cancer who are looking to be a bit more active. Um, so it will be a website that will cover information about what actives are recommended and how to do them and instructions to help you improve your own too kit ias it were

P: Mhmmm

A: so, because its on the internet I’m gonna ask you a couple of questions about the internet and then a couple of questions about my research. Can you sort of tell me about how you are using the internet in your life

P: Well, obviously email

A: Yep
P: Private, and personal, at work constantly

A: Yeah they never end

P: yeah, well work is constant. I was on the bloody phone, you never escape and I suppose its my own issue

I use it a lot for ,um, I spose research- looking into stuff- inquiring, news, um, I use it a bit for catch up TV

A: Oh yeah

P: Iview, that sorta thing, I don’t have a smart TBV but I do have NBN here so um,

A: Yeah, So

P: yeah I mean, so one of my activities is crosswords and I do newspapers, I subscribe to newspapers and I do the cross words using the Internet

A: So you, you would say you’re fairly confidants using the Internet?

P: oh God yes

A: yeah yeah I was gonna say you sound very all over the top of everything.

P: No idea how it happen but I make it happen

A: You seem to have a good learning, much better than some of the other men I’ve met around your age. Um, I was wondering when your your on a website, and you’re doing all that kind of research- do you have a preference for the way that they present information?

P: Um, a simply as possible- I hate all the bells and whistles---

A: Mmmm

P: Um, I reckon a lot of websites- um, are trying to sort of outdo each other -in terms of of funkiness for want of a better word.

A: Yeah I know what you mean.

P: I mean, er, its not a website- but- I go Opera on the harbour in Sydney every year.

A: Mmmmm

P: And the first two were great, and then they started to try and become more of spectacle- and you start thinking, “this producer and director are just trying to out spectacle last year the opera is now secondary. And that’s really, particularly as the price goes up every year, that that really annoys me and the web is very similar.
A: Yeah yeah

P: You know websites that were perfectly good, basic, you know, its got colour and they got all the little bits- frills -and now it takes so long to load cos its got all the frills

A: Yeah yeah, I complete understand.

P: Maybe it’s the outset of Alzheimer’s, but I’m now looking at a webpage thinking “now that you’ve finally loaded- what was I after?”

A>: Mmm yeah yeah it can get pretty verbose,

P: Yeah

A: yeah, I- that’s really interested that you said that. You want the main points pretty obvious. Um so, I’d like to tell you about a couple the ideas for for- developing this program. So I’ll tell you the first one and and get your sortof opinion on that and then I’ll then tell you the 2nd one and get your optioning on that as well

P: Yeah

A: So some websites that are designed to support to improve their physical activity, they offer ongoing advice, so its typically delivered on a weekly or fortnightly basis- um and you know, log in, and you log in once a week or whatever, um you tell you um, the program how you’re going and then it give you tailored feedback and it kinda guides you through the program and usually they are 8-12 weeks. Do you think that’s something you would be interested in it?

P: oh,,, 8-12 weeks sounds like a bit of an imposition

A: Mmm do you think it’s a bit long?

P: One of the things that lingers on from the dietician, is I weight my self at the same time every morning,

A: mmm

P: Well, at the same same stage of my life, not necessarily at the same time, and um, and I put that into an app on the phone and I hate the word “an app

A: “ an app” but yeah

P: and so I mean one of the things with the dietician and this is going back 18 months now, was – “ how I much do you way”- and I said “oh far too much”,

A: Mmm

P: and she said “well how much would you like to weight?” and I said “oh I’d like to t 100 kilos”. And she said when would you like to do that and I said I need to be weight 100 kilos in time for the Chief ministers awards ball cos I know I’m going out to that and we’d be putting people up for awards and I know that, you know, we’d have a table and it’s a good night out. And so that was every time she came she said “how are you doing on the weight and how are we going towards”- and I I made it

A: Oh well done

P: Um, yeah I was 116 when I started, which was pretty gross

A: 16 kilos is not a small amount- that’s -well done

P: Um, it got down to 100 just, 99.993 or something um, and then it sprung up to 102 fairly quickly and it stayed there for a bit, and its running up-my aim- My aim is to weight 105.

A: Mmm

P: er, we are going to have a table at the ball again, I’ll I’m for 102 again, but right now Im just happy if I’m in the 105 range.

A: Mmmm- Mmmm. When you said that um, you thought that the 8-12 weeks was a bit um, bit weird, do you mean like, it, it, do you think that too much of a burden on the participants?

P Yeah I think it’s just a bit long to maintain interest

A: Yeah--- do you think that would be different if it was face to face?

P: Oh God yeah,

A: Yeah

P: I mean um, I mean its big groups of friends and I don’t wanna be sexist, just honest about this,

A: Yeah

P: but you got a 28 year old, sitting there, tell you you know, you gotta loose weight. What are you going to do? You’re gonna loose weight! Its not a computer telling you you’ve gotta loose weight, you’re gonna go ‘yeah---‘ - its like my 54 year old 120 kilo doctor.

A: Mmm mmm yeah, so---

P: I mean automation is great

A: Yeah, I’m not, we’re not looking to replace face to face,

P: No

A: We are more looking to have something that is side by side. Something that you can do in your own time in your home, in your own privacy- um and and so so we’re kinda – that was sort of one idea which is you know more, you’re given advice and reminders to log in every week and you plug in you “ oh I did 5000 steps this week and then the program tells you that’s great an extra 1000 steps compared to last week- that’s awesome- so it will be kinda like that over a period of time tailored to the individual And the idea of tailoring is that you know, you don’t want to give the same physical activity advice to someone like yourself whose a bit in their 70s compared to someone diagnosed in there 40s- so the idea of that so that its that its kinda of –sortof- that you go from A to B to C and its very logical profession.

P: yeah

A: Whereas the other idea that we’ve got, and I’d be really curious to see what you think of this um, its still- contains all the information and the ability to log in and give you’re the tailored information and feedback over time- Um, but the difference is that all the topics are available to you right from the beginning- um- and it allows the persons who logs in to kind of pick and choose what they want to read but it would still be the same about of information about 8-12 weeks worth What do you think

P: Might work better

A: You think it might work better? Could you

P: I think it might work better- cos you throw in um it in with um face to face, I thin that’s were the crunch, cos its really easy its to lie to the computer

A: Oh it is yes

P: I mean, mine does it all the time- I mean but you got someone sitting there- be it the dietician be it the GP –its- human nature is- you’re gonna be much more likely to tell the truth.

A: Mmm, mmm. So um, why do you think, um, you would, so-sorry, it sounds like you were a bit more positive about the 2nd one, I was curious- do you think you would prefer to be a bit more in control of um the information?

P: Big difference -of course I would.

A: Mmmm, mmm- that’s---

P: I mean you go the gym, and the instructor is calling the shots, but you can choose go or not to go, you can choose the sort of class, you can- you have a degree of control

 A: Mmmm

P: even though your control on the day might be a bit limited but even then I can remember times when I used to goo the gym and I’d say I don’t want to bother doing that- I’ll go home now. I’ve done enough for- you know- most of the exercise I know is going to cause me a problem if I keep trying to do it, cos I know you cant do well, if you cant do an exercise well the risk increase phenomenally

A: So because you’ve er reacted that kinda of positively towards the 2nd one, do you think a lot of men would feel better about the 2nd one if they were to do an online program?

P: I guess, its hard to speak for the rest of the world

A: Mmm, its only if you happen to--

P: Um, I would have though so, people, the majority of people in my experience do not like constantly being told, they like to have an element of choice

A: yeah

P: yeah I think that’s quite significant

A: Mmmmmmm- Um, so this will be one of the last questions, so have you participated -0 oh sorry you have of course, you were telling me about that. You said that you liked the program with the dietician cos its was accountability- do you think that you’d like any other kinda topics incorporated into a program particularly in cancer or just general life
P: Ah look I think I’m probably beyond redemption now, I mean, I think the dietician came and she said sorta said “well what do you do?” and I said “well this is how I usually eat but I’m changing it to do this” um, you know she said “fine”, and in a month later she asked “you still doing that?”, and you said “yes” or “no I’ve changed and I’m now doing this and have a discussion about how effective it went. Yeah I think diet and exercise are obviously the main two big issues.

A: Yeah

P: Yeah probably exercise more than diet.

A: Mm

P: Cos if you do a reasonable amount of exercise it seems to me that you can get a way with eating an awful amount of rubbish.

A: Mmmm

P: Not that I would call camembert rubbish

A: *soft laugh* camembert delicious, what are you talking about. *soft laugh-* Ah dear. Um cool, well that brings us to the end of the interview section of the study. Um so to complete the whole process we’d love you option on 4 physical activity messages that we have taken from other sources, they are about a paragraph long and I can mail them to you although I think you’d prefer email from what you’ve told me. Can I grab your postal address to be able to send you the voucher?

*Proceeds to get postal address and wines up thanking participant*