Study 10: Interview Transcript

Interviewee: “A” Participant: “P”

Participant ID: 10 Transcriber: Peggy Rowe- Amy Finlay

A: The first part is kind of general *name*. I was wondering if we could start with a bit of background information about yourself and the processes you’ve gone through with prostate cancer and the treatments that you have had so far?

P: Well, of course the diagnosis comes out of the blue. You go through life hoping that you are never going to get these sort of things and all of a sudden you do. And in my case it came on very quickly because I’d been having periodical PSA tests which was nothing to be alarmed about, and then I had a check in April in one year and then we went away on a 6 week camping trip, came back and had another check three months after the first and the reading had jumped 3 points in 3 months. And the urologist said right, I’m going to do a biopsy and that’s when it all unfolded. He wasn’t happy with the first biopsy and his instincts said do a second one and that’s when he found (it) in the second lot. But there was an infection and his diagnosis was, he gave me the five options, do nothing, brachytherapy, radiation, the radical operation or the robotic treatment. The first one of watch and wait, I said forget that, and I said if you can do the radical check, take it out. Because at that stage which was early August he said the waiting list for the robotic treatment, I wouldn’t get into the Royal Adelaide, until the new year which is far too long to wait. So I’m satisfied that I did the right decision and my wife totally supports me in that, because it was as much a shock to her as it was to me. Because I’d been a blood donor I asked was it was beneficial if I gave a few units of blood and the urologist said by all means, he yes we prefer that if possible. Because you have donation three weeks apart, that delayed the operation for 6 weeks but I was on the table on 5 October.

A: Just gone?

P: No, this is going back 5 or 6 years now. And then in hospital at St Andrews for 5 days, and then home. That’s the hardest part when you come home and adjust because you’ve still got the catheter in, and your follow-up treatment and watching for any post-infection, but I made a good recovery. And the urologist after subsequent checks said right, I’m in the clear. I don’t need to see you unless you think I should see you. Which is the best possible thing. And he said after that second biopsy and after the operation, they do a double check to make sure they’ve got everything, and he said yes, nothing had escaped as far as they can determine

A: That’s really encouraging

P: And he was really pleased with that. Because he said, at that stage, and that’s going back a number of years, they don’t see many patients like that. Usually something else has occurred, and then it is a case of catch up in the body which is not a good scenario. I was concerned because my brother, he was 5 years older than me, he was still alive at that stage but he had very bad extensive bone cancer, all originating originally from prostate tissue. For some reason his urologist never took the prostate out. And that in the end is what killed him. His bone cancer was so extensive and then it went back to the prostate again. And it enlarged so much that they could not operate and it blocked his bowel. And there was just nothing they could do.

A: That’s awful, yeah.

P: I even got him changed to a different urologist. And the second urologist who was a colleague of my fellow, he was aghast that the first surgeon had not taken the prostate out. But it was too late. So the thing that has always bothered me about my brother was back in younger years, we were brought up, grew up, on a dairy farm in Victoria. And in those days we did a lot of spraying for noxious weeds and we used a chemical 245T which had dioxins in it. In those days there were no warnings about the dangers of dioxins.

A: I guess they hadn’t figured that out yet.

P: Nope. It was all pre this scientific age. And whether those chemicals got into his system through the skin because of mixing/diluting chemicals in 44 gallon drums with water and boom spraying paddocks, and with spray drift because no one wore masks in those days. Whether that was the catalyst for cancer, I guess no one will ever admit to or know. But its always been at the back of my mind, that that’s what triggered it off. Because I was in the same boat. I didn’t handle as much chemical, but I didn’t handle it as much. There was such spray drift and exposure on the skin and if you didn’t wash it off immediately, even that’s too late really. Because these things are pretty toxic. And in those days apart from saying use rubber gloves there were no other warnings on the containers. Heaps and heaps of farmers were in that boat. Cereal farmers in particular because they use similar chemicals.

A: Yeah, anything to do with field. Agriculture

P: Yeah, even market gardeners. I always wondered whether it was the original catalyst that started it off. My brother had an early diagnosis. His first issue was he had a mole on his back half way between his shoulder blades. He had that checked and he went to Flinders Medical and the specialist there took one look at the mole and said that’s got to come out. And when she took it out, she said she had never seen one like it before. It was just an ordinary mole on the top but she said, it went down like a carrot. He had something like 60 stiches in the wound.

A: May I ask if you or your brother or you became a bit more aware of looking for the cancer. Who was first?

P: He was diagnosed first.

A: Did that impact how you started looking at your body too?

P: I said to my GP, well my brother has been diagnosed. It’s logical I monitor myself too. That’s when we started the PSA checks. Nothing really showed until this jump of 3 points. And something triggered that.

A: And you said that was 5 or 6 years ago now.

P: Fortunately with periodic checks, Ive just got my most recent one. It was 0.03. Dr Tran, she said they class that as undetectable. It’s as low as they can read. So she said I’ve had a good result. The things is hopefully it stays that way. But of course you never know. You keep checking.

A: Exactly, you just have to keep monitoring it

P: Just recently I’ve had my GP do a complete skin check. Ive had a few things taken off my arms.

A: We’re Aussies, just have to get used to it.

P: That’s right. You just got to keep monitoring. He said, at the very least, every 12 months. The older you get. He says the more frequent you should have it, because they can come up quickly.

A: Well thanks for that. I might move us on if that’s OK. Do you think you view your health differently now that you’ve been 5 or 6 years since the diagnosis and your major surgery? Would that be different compared to before?

P: Yes. You are told by a number of people that have the radical prostate op, that some people never recover physically. It affects everyone in different ways. But I was back on the bike doing junk mail within three weeks. And that’s pushing it. Literally pushing the bike as well as pushing my physical ability to do it. But I am convinced that because of that physical effort, it’s trimmed my weight because I was in the mid 80s, now I’m down to 74. That regular physical exercise twice a week I go out. Tuesdays I do the normal junk mail brochures and Thursdays I do a newspaper delivery.

A: Were you doing that before as well?

P: Yes, but not for very long. But I was determined to try and keep doing it, for my physical activity. That not only helps your breathing and circulation, but your physical muscle movement is keeping me from being overweight, not that I have ever really been overweight.

And I’ve always been a keen bike rider. I used to do that going to school. I lived in the country and I had the three mile ride on gravel roads from our farm to the town where I caught the school bus. If I missed the bus it was 12 miles further to go to the high school. So it was 15 miles. That’s is and down quite steep roads. So if I missed the bus, I just didn’t go home, I went to school. So by the end of the day you’d done a 30 mile round trip.

A: And were you doing that all through your adult life as well?

P: Yeah. Professionally when we moved from Victoria to SA, I then went into the hotel business. I was a concierge in a number of hotels. That’s a job where you are on your feet all the time.

A: Hmm I have a friend in that area. It is pretty intense.

P: You never sit down. Physically you are active and when you have a coach load of tourists come you go to physically move all the baggage from the coach into the hotel lobby, number it all, back onto the trolley’s, up to the rooms, and all that, and the same in reverse when they are checking out. So I’ve always been physically active. I’ve never smoked. Ive never drunk. My urologist was delighted with that because that’s the biggest plus you can have because health wise, he said, we regard you as being in the unique bracket. Not many people haven’t smoked or haven’t drunk. He said, health wise for treatment you are streets ahead of the next patient. Makes their job easier because they know there are no side effects or complications. That in turn affects how quickly you recover.

A: So you talked about that you are still doing your paper run at the moment. How often is that? You said twice a week and how far do you think that might be?

P: Well at the moment, the first run we start at 5.30 in the morning. Because my wife was doing it and she had a fall on morning, she caught a toe on the edge of the curb and went flat on her face. I said right, that’s it, from now on you drive the car and I will walk along and take the things out the back window. Which I do, so I walk most of that route. I would be doing 5 or 6 kms in an hour and a quarter.

A: Oh wow, that’s amazing. And that’s twice a week as well ?

P: That’s every Tuesday morning from 5.30 to 7 and then I go home and load the bike and I do from 7o’clock through till about midday on the bike. That’s 3 and a half or 4 hours.

A: Wow- That’s a very physical morning. It is it is

P: It is, it is

A: One of the questions here is do you do any weights or strength training?

P: No, there is no need to.

A: I was going to say, you are lifting papers, and stuff all the time, you are lifting your bike up so yeah.

P: Well as I said, when you load the bike, each roll of magazines is about a kilo and I have about 50 kilos on the bike, and you push that on the sidewalks where there’s no footpath, rough ground, you are really pushing through soft ground. That’s really good exercise. And up some of the hills I have to do. So that’s really kept me trim and I’m sure has helped my recovery. I go to the Physio every three weeks because working on the farm Ive got lower back degeneration and she just straightens me out. That stretches me and keeps me trim.

A: Does she give you exercises to build up your back muscles again?

P: No, she says what I’m doing on the bike is more than enough.

A: That’s brilliant. Yeah.

P: And I just have to be conscious that I don’t lift things the wrong way, or overdo it. Work within your limits.

A: Have you ever done a formal program?

P: No.

A: if if you were

P: My wife is going at the moment to an exercise physiologist. She goes every Wednesday. But she had a knee reconstruction two years back and which had been very successful and had recovered quite well and to keep her mobile and keep her balance.

A: In terms of the activity, would you say that there are potential barriers that would stop you being active at the moment?

P: The biggest risk is traffic accidents. Negotiating the streets. People just zoom past you and almost take your elbow off. That’s the biggest risk.

A: Hmm And you have also got that external motivator if you need to deliver these papers. If that wasn’t there….

P: Well we are sort of in a routine now. That simplifies it and we psychologically adjust to it.

A: yeah

P: So We can cope with that. The other issue is because we are on a full pension, you need that supplementary income purely to survive. Because your costs, your property rates and fixed costs, they are rising at a faster percentage that what your pension does. The gap gets bigger so therefore you have to trim somewhere.

A: Or you try and add which is what you have been doing.

P: But its not fun for those people who don’t have that ability to earn a supplementary income.

A: No no so not at all. So you said you said that you were back on the bike after your treatment- So you found that the treatments didn’t stop you or physically limit you after?

P: Not really no. Possibly because I’ve got a pretty good level of determination.

A: *soft laugh* where does that come from?

P: After being a farmer all my career until I went into hotels. Because that was the issue in the first week I went into the hotel. Because on a farm when there is a job to be done, you do it, you stay there until it’s done. And I could not adjust to working an eight hour shift, like 7 to 3.30 and then at 3.30 you are supposed to disappear because your time is up.

A: but I can can imagine that on a farm

P: There are guest in the lobby and guests to attend to and you are directing staff. I was there to do it. You just don’t leave at 3.30 and leave guests waiting- and it got to the stage whether the office manager at 4.15 would say, what are you still here for?

A: go home, and I think you’re right- I think that I think that

P: And I had to make that adjustment to be crucial with time management, um, just to conform, with what you’re expected to conform with. And you have to psychologically adjust so that you can tolerate that without it sending you you’re around the twist. Because management’s idea of time management are totally different to the worker actually doing it. You do it thoroughly.

A Just getting back to your activity levels and motivation: If you different have the paper run to motivate you, have you thought about an alternative if the paper run wasn’t there as a motivator

P: Alternatively there is a social cyclist group in town. Because I’m the President of the Probis club at the moment.

A: Sorry, I’m not sure what Probis is.

P: Probis is an offshoot of Rotary.

A: Ahh yep yep

P: When you go through Rotary and you lose interest with them and you are a retiree, then you can go into Probis, because its not a money raising thing, it is purely a social group.

A: yeah yeah I have heard that term before

P: Very good- It’s Australia wide and into New Zealand and its for retirees, Some clubs its men only, some women only, and combined, depending on the district and the number of people.

A: So there is a social group there that you may be able

P: Yes, our club is about 35 members. Probably half are active, half are walking and the other half with gofers and frames….. discusses process

A: If they are still moving that’s important

P: But some of them- There is one chap who comes in with two walking sticks because he’s only just mobile- he can’t get up steps er, but he wants the social activity and the joining into the discussion. We have a half hour for morning tea break and that’s the social event of the morning- the first half of the event is business and show and tell and then half and hour of morning tea then after that’s it’s a guest speaker. Then we finish at ten to 12 to go home for lunch cos you gotta remember that some of them have meals on wheels and need to be home- others stick to their routine for meals or have people who pick them up for meals.

A: well that’s a really wonderful thing that there is a cycling part of that

P: Well *name* is a keen cyclist and that’s his therapy- and there is a retired doctor who leads the pack and the rest of them who keep up. Well blow you *name* and we will catch up the next stop is morning tea. They do 20-30 kms a morning,

A: A morning, that’s great. I mean I’ve just started volley ball again and that social part is really important. So that’s great

P: Going back to this situation here- the fact that *physio* runs the meeting is invaluable- its only a small group but you cannot put a price on the value of that group. She is just a wonderful coordinator, cos she is so concerned about each person. And very discrete, confidential, but at the meeting anyone can talk about anything they want. You can unfold, we have had a few missing people and then they are too sick to come, but they say gee what a whole new approach and understanding. And talking to people who have been through it in various forms.

A: yeah yeah its an experience who have only had it cos its through people who have had a lived experience.

P: Its no different to women who are in the breast care nurse- s an undeniable benefit for them and they need that support, its their story. And if you’re in front of the GP and he says you’ve got this and you’ve got that. As soon as they say that you stop listening to what they are saying. That that is the value of the group, you can listen to contribute if you wish, or just sit there and take it all in or you could talk privately with the others. And that is priceless.

We were all very concerned- About 12 months back *physio* was very concerned because- with the health hierarchy she was having pressure put on her to stop having the meetings here and the time out of her schedule cos she still has to put all her commitments around but it’s the physical- the morning tea and the use of the power and light- and we can’t afford it- but she resisted cos she knew how important this group was. To be able to stay here, cos it’s a central meeting point- and its good to be able to know how to come.

A: I have to admid once she said its at the health services

{P: this is something that the hieracy don’t understand – they are just bean counters. Its in the therapy that the individual person can get can prevent you from being an experience patient somewhere else which is a load on the system.

A: Thanks, I might keep us moving along. I was wondering if you have a sense of the guidelines for someone of your age or or your health condition?

P: Not in those terms, no no

A: That’s arlight, have there been any resources that you personally found helpful?

P: I was confident enough- I’m resourceful enough- I read a lot and yeah- listen to people who speak on the radio and so on, I keep abreast of things. Um, my wife, she’s had a few issues and um, she would see our local GP back in the 80’s and she had an issue- he kept saying there is nothing wrong, and we went to Sydney and she was really sick. We found a gynaecologist- and xrays and she had a massive ovarian cyst that was degenerating. He thought it was ovarian cancer, and said right you’re in hospital next week- he said it was degenerating, he said it was one of the biggest cysts he’d ever seen. And this previous GP never picked it up

A: Yeah yeah it is tricky, yeah

P: Yeah and she had massive blood loss due to the procedure, and you know I’d been a blood donor as its something that I’m very passionate about that young people should do that. Unfortunately when I had the prostate thing they said bye bye

A: yeah

P: which I was a bit sad about, and in regards to your question, I just sorta been a self help program. A doctor said if you’ve found something and its working for you to keep doing it.

A: yeah

P: I got the blood results last week, the doc said I can’t find a thing wrong with you at the moment you’re going well.

A: So obviously a lot of these questions are about physical activity which leads me to what I’m doing in my Phd at the moment. So me and my team are designing um a program that’s online- um and it’s a resource for men who want to become more activity who want to become more active. It will give information and demonstrate how to do certain activities if you were interesting in doing that type of activity. So firstly I’d like to ask you about your Internet activity in general and then I’ll give you sortof the pitch of our two ideas I’d like to get your opinion on our research. So can you tell me a bit about how you’re using the Internet at the moment?

P: At the moment I’m not using the internet. My daughter does, she uses with wifi- she is a wizard with it. Um, I’ve just got this smart phone to go with the paper delivery because they track us now up and down every street and um I’m slowly mastering the smart phone and its various foils that that’s got. But, as far as the internet goes and the NBN- there are still issues with that in our locality.

A: yeah

P: I’ve got a computer sitting at home that a friend of mine gave me, um I want to get using that and um, but how quickly I can get up to speed remains to be seen because you need to practice it every day. Cos

A: yeah yeah cos it’s a learnt skill, so you have to practice

P: In my younger days I was in the young famers association in victoria and I was a secretary at various times and I was quite a good typist back in those days. So the finger work will come back. But yeah its just making that mental adaptation to the various screens though.

A: You seem pretty determined to learn so…So

P: My objective in life is – I’ve had a life insurance policy that I’ve been paying for years and I want to be able there at 95 when it matures. *Soft laugh* to get the pay out

A: *Soft laugh* fair enough

P: That’s my motivation *Soft laugh*.

A: so if you- what are some of the reasons that you don’t use the internet? Access? Or interested?

P: I’m interested in it cos it’s the way its going and with all the government departments- they assume the that everyone’s got the Internet. A lot of people haven’t got access. And here in *rural name* there are black spots everywhere.

A: yeah

P: Its it’s a massive problem. Cos you’re supposed to do everything online.

A: So, where do you think people, and If you have to access something on the internet, and you don’t have a computer- would you go to a library?

P: You can but its very limited? The university of the third age, U3A there is one in place namethey have courses but they cost money. And that’s another issue, people are watching every penny these days um, you gotta justify that expense. There should be more free courses, there are some here in *place name* but you can’t always getting to them when they are on.

A: Yeah with fuel costs and all that

P: It is a limiting factor. Local government could pick that up if it was subsidised from the federal people but it’s the federal people who introduced the NBN and they’ve stuffed it up big time. They really have and if they expect people to access computers and do their business especially government business by computer. Pay bills. The banks are continually telling us that we are going to have cashless society within 5 years but I don’t think that will every happen. But banks themselves will never ever ever have paperless offices, ever. They always have forms for something.

A: They certainly do. Well, that’s actually really interesting cos if you’re someone who hasn’t really engaged with the Internet but you want to learn. What do you want a program to look like- what would sort of features would be good to be on a computer screen?

P: It needs to be completed devoid of interference, that’s the problem with the smart phone at the moment. I’ve recently googled looking for a second hand caravan, and you’re going through gum tree and you just get on the picture you want and you try and scroll and one of these damn adds pops up on the screen and you just just touch it one and poof-

A: yeah it takes you

P: it takes you to another page- that has precedence over what you’re looking at.

A: I mean the good thing about our website is that we wont have adds we won’t have that kinda thing

P: if it’s a dedicated site that blocks outside interference that’s the first hurdle

A: Absolutely, yeah. And um this has come up with a couple of other gentleman I’m wondering if you think similarly. Its sometimes frustrating to go onto to a website and not be able to find the information. Would you agree with that?- would you want something…

P: If it can be simplified so that its obvious step-by-step procedure is- it shouldn’t be an issue if you cant follow it logically.

A: yeah I agree,

P: Educational ability at this time in life, cos you’ve got your degrees already, you don’t have- haven’t known life without computers

A: its true, I can’t remember a single time without

P: Its natural to you, you’ve grown up with it, but you’re dealing with the senior section of the community and its foreign to them. Put it in that way. Its like going back to primary school again, you’ve got to learn you’re A B C’s. It’s the same type of thing. Young people these days, and professional young peoples in their 20’s and 30s- they don’t understand that. They might proficient at what they do, I don’t critise them for that- but they don’t understand that its so much more difficult for people who haven’t grown up with computers. But still have the desired and the capacity to learn. I’ve met a lot of chaps here, and they might be a bit frail but they’ll be a sharp as a tack. They’ve go the ability. And that’s partly, of what keeps me going. The more active I am, the longer it will be until I get dementia hopefully *soft laugh*

A: *soft laugh* yeah yeah. Well thanks for that so far. I really appreciate this as I need lots of different inputs and its really valuable. Thank you

P: This is born our *physios daughter* is doing study sahmri-

A: yeah

P: and she just said now the daughter has been offered a scholarship to Harvard.

A: Wow, that’s amazing

P: She comes up once a yeah to us to explain what she has done in simple terms. A wonderful delivery. And that’s flowed through to what she is doing and has been noticed overseas to present a paper. And someone there has picked up on her ability.

A: I think communication is important I think youre right. I think its easy for people to get caught up

P: That’s right, and this is the good thing about *oncologists name* the other day- concise and direct. Excellent delivery.

A:Mmmm. And I think she explained things very thoroughly and made sure she wasn’t using big medical terms- language we can understand

P: Laymen’s terms

A: yeah yeah, cos not everyone’s been to medical school- yeah I thin you’re right with communication. So I might just ell you about the two ideas that we have- and you can tell us what you think of them. Um so the first idea is that um, you log on and it will be er for about 8 weeks

P: Mmmm

A: and you log on once a week or once a fortnight and er the program will take you from- in a logical progression. So [module] A would be an introduction, so if you’re very active like yourself we won’t tell you about the basic stuff, we will try and meet you where you are. Its very A to B to C across the 8 weeks- so would that be something that you might be interested in?

P: I’ll say yes with some reservation *soft laugh*?

A: That’s alright, please tell me about those reservations what are your thoughts.

P: Just so I can cope with it- but my daughter’s er, she’s just finishing- she got told yesterday that her job on contract that its not going to be extended which is extremely disappointing for her. She’s be living with us in September for a little while while she goes get another contract so in that time, I’ll see if we can sit down and get me started on this computer

A: yeah yeah- so that’s our first idea. And then the 2nd idea is – its basically the same, that you log on and that there is about 8 weeks worth of information there. I forgot to say in the first and the second one is that you would type your physical activity in for that week into the program and it gives you feedback on it.- and the feedback you get is different to someone else- if they were younger or older or if they had arthritis or something. Um, but the 2nd idea, instead of A to B to C, everything is open all at once and you can pick and choose what you read about.

P: for your interests

A: for your interests- would that be something you’d be more interested in compared to the first one?

P: Mmm, hard to say.

A: its alright, there is no right or wrong

P: If it’s the case of cherry picking, its about getting enough of what you need. You know, you might not know unless you saw it all.

A: yeah true- So I guess it depends on personality, or if you’re confident…

P: Its hard to say,

A: That’s alright there is no right and wrong, we are just curious

P: Yeah, yeah

A: yeah, um, so I’ll move us onto the next little bit. So these are some naming ideas, I would love for you to have a look at some of these. I was wondering if you could tell me a little bit about what one catches your eye, and ones that no. I think marketing and telling what the program is, so if it doesn’t communicate what is its, its hard to see if its going to be useful for you.

P: Erm, do you want me to mark these. The first two, one two and three

A: so you like the full names, yeah. What are your thoughts on exercise med- medication in a way.

P: Well that’s an alternative for people who cant’ get out to walk or ride a bike or get to a gym class- more just for those limited in a house. Cos that’s what my wife was doing after her knee operation. You’re not mobile for a few weeks but you still need to do those physical exercises in the house. They’ve got these stretch bands now which

A: Therabands yeah

P: There are many alternative ways you can use them.

A: Have you ever given them a try?

P: No not really

A: Not really for you?

P: nah nah, but its been helpful for my wife and she looks forward to seeing the exercise physiologists. 6 or 7 machines and she really looks forward to that physical part of the therapy.

A: Mmm

P: it gets her up and active, and helps the circulation um, and she feels better for it.

A: Yeah, so that brings us to the end of the interview part.

*Processed to complete survey. Thanks participant for their time and give you the thank you*