**FILE DETAILS**

*Audio Length: 28 minutes*

*Audio Quality:*  *High*  *Average*  *Low*

*Number of Facilitators: One*

*Number of Interviewees: One*

*Difficult Interviewee Accents:*  *Yes*   *No*

*Other Comments:*

**START OF TRANSCRIPT**

**[FC006\_\_1]**

Facilitator: Okay. Do you have any special areas of interest or work that you're doing?

Interviewee: Not really. I guess I'm interested in everything, which is part of why I work here, because I get to do everything [laughs].

Facilitator: Wow. That's interesting.

Interviewee: So that's good. Yeah.

Facilitator: Yeah.

Interviewee: But I don't have a specific area of interest. I mean, I do quite enjoy working in the space of - in cancer genetics, but I quite like other areas of genetics as well. So it's good to be able to do a bit of everything.

Facilitator: Yeah. Okay. Well, have you - or are you aware of the new guidelines around using low-dose aspirin to prevent bowel cancer?

Interviewee: Yes.

Facilitator: Yeah? Can you tell me about your understanding of those guidelines or what you know about them?

Interviewee: Yes. So I know that the NHMRC published new guidelines for the prevention of bowel cancer - prevention and early detection of bowel cancer. I think it was last year that they were published and I know that within that there was a recommendation that every person over the age of 50 or from 50 to 74 should take low dose aspirin on a daily basis to help prevent - well, to help prevent bowel cancer. Obviously, only as long as there's not contrary indicators with other medications and - or other health conditions and I understand that it takes about 10 years to get the effect of taking the aspirin, so you have to be taking it for about 10 years before it has any impact. So…

Facilitator: Okay.

Interviewee: …that's my understanding, I think.

Facilitator: Right. How did you find out about the guidelines?

Interviewee: How did I find out? I think it was probably because my supervisor had actually been at a familial cancer conference and knew that the guidelines, the new guidelines, were coming out, so we were sort of watching for them. Then when they came out, she circulated them, so we all had a read. Which was good, because I think there must have been a particular case that came up around - to do with some other issue around bowel cancer, familial bowel cancer, and management and surveillance and that kind of thing. We were waiting for these new guidelines to come out to be able to rely upon them. Yeah.

Facilitator: Okay. Because - you said that it was your manager, right, who went to a conference?

Interviewee: Yeah. Yeah.

Facilitator: How do you usually find out about new guidelines when they come out? What is…

Interviewee: Yeah. That's a really good question. The information comes to us in all sorts of different ways. It is - sometimes it can come through the Human Genetics Society in Australasia. There will be something on one of their sites that we - or one of the newsletters that we pick up. Sometimes it will be that you'll see on - or that I might see on social media that some new guideline or some new position statement has been published. I also sit on the Ethics, Education and Social Issues Committee of the Human Genetics Society of Australasia and so I get some awareness of some of the major policy activities that's happening around the place.

So sometimes I'll pick it up through that, but, yeah, there doesn't seem to be a really solid, consistent stream of where the information comes from. It comes from a whole heap of different angles.

Facilitator: Yeah. It does sound like that, that you do have to refer to several platforms and you're relying on several publications and just streams of knowledge to keep yourself up to date.

Interviewee: Yep.

Facilitator: Yeah. So how do you usually incorporate new guidelines into practice then, because there is so much information, I guess?

Interviewee: Yeah. So a couple of ways, I guess, we - first of all, we have quite a small team here, so at least we can promote the awareness, so spread information to others. One thing that my supervisor did really well this time was actually did a bit of a summary cheat sheet, kind of thing, around key aspects of the guidelines that - for us to be aware of and I refer to that quite a lot. With respect to this specific guideline around the recommendation to use low dose aspirin, we actually already had a fact sheet around the use of aspirin as a preventative for bowel cancer and…

Facilitator: Oh, wow.

Interviewee: So I recently was just updating that, so we were about to just get that signed off in terms of just wanting to seek peer review to get that signed off and then that will be a fact sheet that we can use to provide to patients. So…

Facilitator: So you actually create one for patients.

Interviewee: Yes.

Facilitator: Oh, that's interesting. I would probably like to see that then. After - maybe after you have it all done, but that is a - I haven't heard of anyone doing that before. Yeah.

Interviewee: Oh. Yeah.

Facilitator: That is interesting.

Interviewee: We actually had a very interesting thing recently where one of the oncologists was asking us about how does this - how do these guidelines relate to the outcomes of the ASPREE trial.

Facilitator: Yeah.

Interviewee: So that's another reason why we have found that it's been really important to make sure that we're clear about where the different - the evidence base for the different things have come from, because the ASPREE trial, it doesn't really - they're, like - they're not contradicting each other, but I think that if you were out there in medical land, people have started to think that the ASPREE trial means that asprin is not helpful in terms of preventing chronic disease and that kind of thing.

I don't think that they realise that the cohort of people that that trial was undertaken with is a completely different cohort to who we're recommending use of low dose aspirin for an all those sort of intricacies.

It's hard to pull that apart, so that was something that really forced me, anyway in particular, to kind of look into it and make sure I knew what I was talking about, make sure that we had all the right information and, I guess, what we were concerned about too on top of that was this sense that if there's one thing that has been talked about out there in the public in quite a negative way and we're making a recommendation that seems contrary to that, then we need to have something that backs that up and that gives people a bit of support or a bit of guidance to help them understand why we're recommending something that sounds contrary to other public messages.

So that was why we felt like it was important to update that fact sheet.

Facilitator: Yeah. Have you noticed that patients have brought it up with you or…

Interviewee: Not so much patients as much as other clinicians really.

Facilitator: Oh, yeah. Okay.

Interviewee: Yeah.

Facilitator: That's interesting. So I'll just go back to the questions. I was just asking you about what you were saying…

Interviewee: Yeah.

Facilitator: It's pretty.

Interviewee: [Excellent].

Facilitator: Yeah. So what are your professional opinion of the guidelines? I guess you can look at the guideline sheet as well that I sent to you and if you want to…

Interviewee: Yeah.

Facilitator: …look at that and kind of do a little think out loud. If there is anything on there that you missed or that you didn't know about, if you could comment on that and then we can go back to the opinion question.

Interviewee: Yeah. So, yeah, just looking at the fact sheets…

Facilitator: Yeah.

Interviewee: …that - I mean, the top section looks okay. I guess the thing is just sort of saying that people who are at average risk that - what does that mean or the question of does that mean? How do you know whether someone's at average risk or high risk? My understanding of the guidelines is that it - it's basically for people aged 50 to 70 in the whole population. Like, everyone. So I guess that that's just one thing. I guess the question about it, which it's contrary indicators is not there. You wouldn't want people to go off taking it if there were other - if it was going to affect their health in an adverse way. So I feel like that bit's not there.

So the recommendations for those at higher risk. Yes, I think that that's really helpful, the statement, the dot point about that they should begin aspirin when they begin colonoscopy screening, because I feel like that that's something that's missing from the broader guidelines. I feel like - and that's something that I was looking for and trying to get some evidence about recently, because the case that I had was a woman who was about 34 who'd had quite an aggressive bowel cancer and my recommendation back to her after seeing her that she and maybe her siblings could consider taking low dose aspirin as a preventative agent.

That's when the oncologist questioned me and said, oh, where are you getting this from, sort of thing? When I went to look back to the get the evidence about is it safe to recommend it for younger people, it was very hard to find that information. So I think that that's really good to have that clarification [unclear]. Yeah. So, yeah, I think that 600 mgs a day versus the 100 milligrams a day, I guess that that's going to the CAPP2 trial where you know that exactly - that 600 milligrams a day has been shown to be effective, where you could have something more - I mean, something much lower - a much lower dose. I don't know. It's just useful.

Then you've got the big box about aspirin should be avoided within those - with those conditions. I guess it's just wondering whether that needs to be linked more with the top one. So I guess the way I've looked at it is I've kind of looked at the top box and then the one on the left and finally got to the one on the right. So I could have missed that really important element, if I'd already made my mind up [laughs]. You know? So that's my only thing. Yeah.

Facilitator: Okay. Interesting. Thank you. So I'll go back to just asking you your professional opinion.

Interviewee: Yeah.

Facilitator: So this is just where you get a bit personal in your own opinion about the guidelines and what you think about them, considering the evidence as well, I guess. So you did mention the CAPP3 trials or the CAPP trials.

Interviewee: Yeah.

Facilitator: So…

Interviewee: Yeah.

Facilitator: Yeah.

Interviewee: I - it's a bit hard for me, because I'm not actually a doctor. I'm a genetic counsellor and so my professional opinion is based on only kind of what I've read and my interpretation of the evidence. So, I mean, I think from what I was reading recently, that the evidence is fairly robust in terms of the 600 milligrams a day. Yeah. Where was the other thing I got about the 100 milligrams a day? I think that - as I was reading through - I was feeling like most of it was information that I already knew. So I was reviewing the evidence recently and I was feeling like it was information that I already knew.

So I don't think that there's - I think that when I very first heard about the recommendation, I was a bit surprised. I thought, oh, wow, for everybody? On what basis? But then when I read the evidence, it made sense. So I thought - so it seems a reasonable recommendation.

Facilitator: Okay. All right.

Interviewee: Yeah.

Facilitator: So when you consult with patients, you have mentioned that you have recommended it to younger people. Have you started to recommend aspirin, low dose aspirin, for people that are average risk of colorectal cancer as well?

Interviewee: Yeah. I mean, I guess we don't see that many people who are at average risk, because we're in a - we've been referred people who are already at increased risk. But certainly if that's the way I phrase it, I'd say that the new guidelines are that - that everybody from age 50 should be having this. But - and often if I'm recommending to people who are younger, I will say - in that way, I will say the guidelines are that for everyone aged 50 to - from 50 years of age to have low dose aspirin and to - help prevent bowel cancer. However, we know that in people who have higher risk because of their family history that it would be reasonable to start at a younger age.

So that's the way I sort of explain it. Yep.

Facilitator: Okay. What do you think patients feel about - or how do you think they feel about taking aspirin preventatively?

Interviewee: Yeah. I think most people that I've spoken to have actually been in some way surprised that - not worried. I guess because - surprised that something that seems so commonplace, I suppose, like aspirin, could actually have a significant effect or is like a key recommendation. Yeah. So - but it doesn't seem to - they don't seem to feel like it would be something they - that they couldn't adopt or couldn't accept. It seems to be something that seems quite achievable and manageable. Yeah.

Facilitator: Yeah. Yep. Like, people are pretty receptive to the idea, although they're surprised?

Interviewee: Yeah. So in terms of - yeah, I think so. Like, but, in general, they're like, oh, wow, okay. That seems like a simple thing to do and then surprised that such a simple thing could have such a good effect.

Facilitator: Right. Yep. Do you think it's because aspirin has also been around for a very long time?

Interviewee: Yeah.

Facilitator: I think so and just that everyone is like, oh, aspirin? That doesn't - that - I think most people probably think of it as a fairly harmless thing.

Facilitator: Oh, yep. Okay. What do you think about the harms and benefits of taking aspirin? Do you - are you aware of them? I mean, I guess you are, because you knew about the contraindications a bit. But what do you think about - or how would you explain that to a patient?

Interviewee: I would certainly just make sure that they consult with their GP to - before they start taking it, so that's what I always say is that it's important to speak to your doctor before you start this. That for some people it's not a good idea. So maybe if people have high blood pressure or have a tendency for bleeding or that kind of, it can not be a - it can be a bad thing to take aspirin, so it's really important to do it with medical supervision. Yeah.

Facilitator: Yeah. Okay. Okay. I guess, we can go to the EFT, the other document that I sent you.

Interviewee: Okay. Yep.

Facilitator: Yep. In this one, I'd like for you to do a similar thing, where you work through and think out loud about it and thinking about it as well, in terms of it being something that could help you explain the harms and benefits to patients, whether or not you agree with that statement. It might not be something you want to use. It might be - and I just want to hear your thoughts around that.

Interviewee: Okay. Cool.

Facilitator: Yep.

Interviewee: So this is an expected frequency tree showing the effects of aspirin on the incidents of events over 10 years of taking aspirin for at least five years in Australian men and women aged 50 to 70 years. So is this people taking daily aspirin for at least five years?

Facilitator: Yep.

Interviewee: Yep? Okay. Because it doesn't - I don't know. I feel like I need the word daily there.

Facilitator: Okay.

Interviewee: Sorry [laughs].

Facilitator: Yeah. No. That…

Interviewee: So over 10s years of taking daily aspirin or aspirin daily for at least five years. Okay. So if you've got 10,000 women and you've got four conditions there, bowel cancer, heart attack, stroke, bleeding from the stomach and gut. Then if you have no aspirin, so that means that 88 out of 10,000 women have had bowel cancer.

Facilitator: That's right. Yep.

Interviewee: But those taking aspirin, only 66 of those taking the aspirin or is it 66 out of 10,000 women who were taking aspirin had bowel cancer. So that shows you the difference between the number of people who have been affected where they've taken aspirin or not.

Facilitator: Right.

Interviewee: Whether they've taken aspirin or not. So you can see that the number is lower in the aspirin line. Except that - and then the - obviously the impact seems less significant to people in relation to heart attack and stroke. There's a lot of difference between the two numbers for heart attack or for stroke, sorry. Then you can see that the bleeding from the stomach and the guts for women that taking the aspirin was actually - has - was worse, had an increase in - an increased chance of having that problem, if you took aspirin. So - and similar story for the men, I suppose.

So it - I guess you could then interpret that by taking aspirin that that could be a bit protective against bowel cancer and somewhat - like, more protective in the men against - for heart attack than it is for women. But doesn't make a big difference with regard to your stroke risk and certainly it has an adverse effect in terms of your risk of bleeding from the stomach and the gut.

Facilitator: Yep. Do you think…

Interviewee: That's the way I read that.

Facilitator: Yeah, yep. Do you think it could be something that could be helpful to explain the harms and benefits to patients?

Interviewee: Yeah, I think so. I think it could be helpful.

Facilitator: Okay.

Interviewee: Yeah. As long as it's presented the right way, I think it could be helpful. Yeah.

Facilitator: Yeah. Do you think it's…

Interviewee: So…

Facilitator: Yep.

Interviewee: So I guess the thing is is that just to - the important thing is that it needs to be clear that this is not just trying to demonstrate all the benefits. It's actually trying to demonstrate the impact on a range of different types of condition and that it can be good for some things and not for others.

Facilitator: Right. So do you think when you first looked at it, was that obvious or no?

Interviewee: I don't think it was obvious. It was only when I started going through the numbers that I started to think - I started to realise that.

Facilitator: Yeah. Okay. So if we could make that stand out more.

Interviewee: Yeah.

Facilitator: Yep.

Interviewee: Yeah.

Facilitator: Then you said the daily aspirin use to change the wording a bit.

Interviewee: Yeah.

Facilitator: Yeah. Okay.

Interviewee: Yep.

Facilitator: All right. So just - I think I had one more question and that was it, because I skipped it and I was, like, oh, let me go back to that. So what is a - like, a specific trigger when you're meeting with a patient that causes you to talk about preventative strategies or to bring up something like this?

Interviewee: Well, I guess that a lot of what we do here in genetics is about - I mean, when we're assessing a family history in relation to risk of developing certain types of cancer is that for some families, we can offer them genetic testing, which will give them - potentially give them a bit more clarity about their risk. But for other families or if we don't get an answer, then I guess we're just assessing risk based on statistics and empirical evidence and then the next question after you've kind of given someone an assessment of their risk is, well, what can they do about it?

So one option of what you can do about it is to have enhanced surveillance and another is to take on preventative strategies. So I guess it kind of comes out of - as being holistic in our risk assessment really is that you're sort of saying, well, based on your family history, these are the types of things that you - you know, this is what your chance of developing this condition is and we would recommend that to try and identify that earlier that you have an annual colonoscopy and we also know that taking daily aspirin, low dose daily aspirin, can help prevent bowel cancer. So that's the way I would manage that.

As I said, I will often normalise that as well by saying - and, in fact, the new bowel cancer prevention guidelines say that everyone from the age of 50 should be taking aspirin on a daily basis. Yeah.

Facilitator: Yeah. Okay. Well, that's the end of the questionnaire actually, so…

Interviewee: Cool.

Facilitator: …thank you so much for your participation. I'll turn…

**[FC006\_\_2]**

Interviewee: Once this advice came out - I was - yeah, an earlier doctor. Like, I - well, yeah, was on to it. Felt like I had to start telling people. I think that's probably, as I said, it seems like quite a simple thing to do. Yeah. So…

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Interviewee: Because I don't feel like I know enough about the evidence. So what I do is I raise it and say you can take - you might like to speak to a breast specialist about the options or the benefits of taking this. So - but I don't give the recommendation that this is - you know? This is - like the details of what the option is. Like, I just don't have enough information. Whereas I feel like with the aspirin and the bowel cancer prevention, it seems much clearer.

Facilitator: Right. That could be something that prevents other people from recommending aspirin as well, because you know a lot about it and have read about the evidence and you - it might be the one thing that causes you to say, hey, I feel confident in recommending this versus…

Interviewee: Yes.

Facilitator: …like you said, the Tamoxifen, where you haven't done as much research.

Interviewee: Yeah.

Facilitator: Yeah.

Interviewee: So I think that, yeah, definitely there's a - for me personally on lots of levels in my practice there's a level of comfort when I know that I know the evidence or I know the details or I with - you know? Like, I - I'm leaning on something that's kind of a bit robust, you know?

Facilitator: Right.

Interviewee: Whereas if I don't feel like it's an area that I know a lot about, I feel very - I don't feel as confident being as - I suppose as directive. Yeah.

Facilitator: Right. Yeah.

Interviewee: Yeah.

Facilitator: Well…

Interviewee: So…

Facilitator: Thank you so much for your time and…

Interviewee: That's okay.

Facilitator: …if you would like, I could send you a summary of the project after we write it up.

Interviewee: Yeah. That'd be great. Yeah.

Facilitator: Yeah. That'll…

Interviewee: I'd love to see it. Yeah. It would be good.

Facilitator: Yeah. That'll be at the end of the year, close to the end of the year, once we have every - all of the data and have everything analysed, but I can send it out to you.

Interviewee: Excellent.

Facilitator: Okay.

Interviewee: All right. No worries.

Facilitator: Well, thank you so much.

Interviewee: Thanks so much.

Facilitator: Yeah.

Interviewee: Okay. All right. See you.

Facilitator: See you, bye.

Interviewee: Bye.

**END OF TRANSCRIPT**