HWM05 02-Nov-2020 Interview transcript

RB: So that first one the University of Toronto one, have you got that… [pause due to technical problem]… So have you got the University of Toronto Atrial Fibrillation Severity Scale? It's the one you had before…

HWM05: Yeah, got that

RB: So the first question on there is are you male or female?

HWM05: Male

RB: I know, so I was going to say we normally get more choices than that these days but er, it's a bit old fashioned

HWM05: Yeah I know, just male

RB: And I don't need your full date of birth but can I record what year you were born?

HWM05: 1970

RB: Fine thanks you very much. Um and the third question on there is "Are you in AF currently?

HWM05: Yes.

RB: Can you tell when you're in AF?

HWM05: Yes

RB: And have you been having it a lot lately?

HWM05: I can never.. do you know… It was found accidentally back in January, and I never knew I had it. I never knew that I was in Afib when I did have it. And then from when they started messing me about, gave me a cardioversion and put me back to "normal", there was a difference, I could feel a bit of a difference. Um that lasted a couple of weeks and then I went back into Afib and had Afib the worst I'd ever had it

RB: Oh really

HWM05: So really felt it. Like dizzy, faint, out of breath. Um and then they, they decided to.. next best option was to have a cardioversion.. um the [wife corrects from background] the abilation

RB: Yeah

HWM05: Um I had the abilation which put me back into… I had the abilation and the cardioversion at the same time so when I came out the operation I was back into normal pattern. Um a week later I was rushed into hospital, and I had tachio.. oh, fibrillation

RB: Right

HWM05: Where my heart was racing, so they then had to give me another cardioversion, put my heart back into normal rhythm, uh which was successful. And then a week later I went back into atrial fibrillation and I was back in hospital again.

RB: Whoah. Alright. You've really been through it then

HWM05: Yeah so it's not been, it's not been a great experience to be honest

RB: No

HWM05: From a finding that was accidental…

RB: How was that found out?

HWM05: I had a pain in my chest and it was, it happened to be a pulled muscle in my shoulder but when I phoned up my doctor she advised to phone 999 'cause it was a pain in my chest and then when the ambulance crew came they put me on an ECG and found that I had an irregular heartbeat um, so they took me into hospital where they run more tests and confirmed that it was AF. Um and I'd only pulled a muscle in my shoulder that was causing me the pain and the problem. Um and then I sort of just told you the story kind of what's happened since then, so… But I never like, right from the beginning they asked me lots of questions like being out of breath, struggling to walk or feeling dizzy or.. never had any of them symptoms, never.. occasional just felt my heart race a little bit maybe when I over-exerted or such but not.. nothing that I was ever worried about I just sort of "oo that went a bit quick then" and that was it really

RB: Yeah

HWM05: But then since they've messed me about… or been messing me around, it's very much noticeable

RB: Right, right. So you strongly associate the worsening of your symptoms with the start of being treated for AF?

HWM05: Yeah, a hundred percent.

RB: Yeah. So question three on there… or question four on there is how do you feel about your life at the present time?

HWM05: It's ok, um… It's, the Afib does concern me more now than what it ever did, obviously. And I did.. Yesterday I did say that… I got a Fitbit watch so I could sort of watch my heartrate and things and I did say yesterday it's just really starting to annoy me now, it's just constantly getting on my nerves, my heartrate goes wild and then settles back down and then goes wild again. Um and I do notice it, I can sit there and without looking at my watch I know what it's going to say then I look at my watch and think, yeah I'm up at 129 beats per minute or something like that, so…

RB: Yeah

HWM05: And before, prior January, I never sat and thought oh, you know, I just.. I said it was just the odd occasion where I thought, you know "That beat…" you know "My heart went quite quick then" and that was it, that's all, so… I do associate with the work I've had done…

RB: Mmhm

HWM05: ..with the problems that it's causing me now.

RB: Ok, ok. And how often do you feel your irregular heart beat

HWM05: Um, almost constantly now

RB: Right

HWM05: After the abilation al.., yeah almost constantly

RB: Right, right.

HWM05: It was, the abilation was done four… it was the 2nd of [month], so it was just over four weeks ago. Um, and um what, I've been back in twice since then but what the consultant has said is it is, it's possible for the procedure to make it worse before it makes it better so I'm hanging onto that analysis until hopefully that it does, but it's certainly not made it any better

RB: No, no, ok. And how many times have you actually seen the consultant in the last year with your irregular heart rhythm?

HWM05: What, since January? Um one, two, three, four, probably half a dozen?

RB: Mmhm, so yeah you've been…

HWM05: So when I went back into AF, I went back into to see him and they done some tests and confirmed that I was back in AF after the cardioversion and then I went to see him about the abiliation and then obviously after they done the abilation he come and see me on the ward and then the following week when I got rushed into A&E he come and see me then… and after that he came and see me then so I'd say half a dozen times?

RB: Right yeah. Ok, so I'm going to move on to the symptoms that it causes you now

HWM05: Yeah

RB: In part C of the questionnaire. So palpitations, do you feel that you have palpitations? You're obviously aware of your heart beat.

HWM05: Yep

RB: Yeah and how often do you.. are you aware of that constantly or…

HWM05: Yeah, all day really yeah

RB: Yeah. And does that… do you have shortness of breath when you're sitting down?

HWM05: Um I have experienced that, not all the time. Yesterday I had an episode where I had to lie down, put my feet up

RB: Right

HWM05: And I actually fell asleep so, I felt really tired, drained

RB: Yeah ok and then as you're moving about the house doing sort of jobs about the house or if you're at work do you feel short of breath?

HWM05: Um, I wouldn't… if I exert a little bit more than normal then I would, yeah

RB: Yeah

HWM05: But, I've got quite a physical job anyway

RB: And before you were diagnosed with AF, did you ever feel short of breath while you were doing your job?

HWM05: No.. I wouldn't say, I wouldn't say I was short of breath I just.. kind of working hard and then think, you know, just where I've sort of exerted myself with my age a little bit, so I'm more aware of it now than what I was before, definitely

RB: Sure

HWM05: It's a lot worse now than what it was prior January

RB: Right and you definitely think it's got worse now it's not just that you're aware of it?

HWM05: It's got worse definitely.

RB: It's got worse. Yeah. And um if you're doing.. Do you do any exercise at all?

HWM05: Just, I was before the abilation doing couch-to-5k but I'm not doing that anymore

RB: Ok and out of interest what made you stop doing that?

HWM05: Um we had a bereavement in the family, my sister weren't very well so I spent a lot of time at the hospital and that , so it's just a lot of time spent.. and I've not really managed to get back to it. Although since the operation I've not really felt fit enough to .. to be able to go out for a jog or.. so..

RB: Yeah, well it's early days isn't it, what was it, just a few weeks ago wasn't it?

HWM05: Yeah, a month ago but I, I've, I spend a lot of my time, like, very tired

RB: Yeah. And before you had your diagnosis of AF, so before January, did you do any exercise then?

HWM05: Yeah, I was like walking and um, done a little bit of football training and things so I was always sort of out and about, an…

RB: What do you do for work [name]?

HWM05: I'm a bathroom fitter, so I'm..

RB: Oh ok.. that's up and down a lot

HWM05: Up and down stairs

RB: Yeah, and getting in little spaces

HWM05 I get through a lot of steps in a day, yeah

RB: Yeah, yeah. Um and you mentioned yesterday that you felt very breathless and then fell asleep on the sofa. Do you often feel breathless when you're resting, just when you're resting as opposed to when you're doing something?

HWM05: Yeah, I started getting headaches and getting very lightheaded to the point that I had to lay down

RB: Yeah. And other than the time you had the pulled muscle, have you ever had chest pain or pressure in your chest because of AF?

HWM05: No

RB: No. That's something you don't have. So I'm going to move on now and have a look at the other questionnaire

HWM05: Yep

RB: Which is the one that starts with the words "Effective English EQ-5D-5L"

HWM05: English version UK

RB: That's it

HWM05: Yep

RB: So this one on the first page it says EQ-5D-5L and then on the second page there's different activities and it asks you whether you have difficulty doing them or not

HWM05: Yep

RB: So the first one is mobility, so looking at those options would you say that you have any problems with walking about?

HWM05: No

RB: So if you're just walking about your AF doesn't cause you any problems?

HWM05: Um, I've got.. again, it's like a.. I can feel when my heart beats quicker and there's like a null, a null pain but not anything that stops me walking or.. you know, I can still get around and…

RB: Mmhm. Does it slow you down?

HWM05: Um a… something I never really noticed before I just sort of thought getting older I'm probably just slowing down naturally? Um but when they first, the first cardioversion they done, when I came out of hospital I sort of rested that day and the next day I took the dog out for a walk and I did feel like a little bit lighter on my feet and it did feel, I did feel sort of healthier, yeah

RB: Right ok.

HWM05: So there was a noticeable difference there

RB: Right, that's interesting. Then with self-care, do you have any problems washing or dressing yourself?

HWM05: No

RB: And usual activities, so work, leisure or family activities, it sounds like you.. that is being affected a bit by your AF, would you..?

HWM05: Yeah

RB: Yeah, would you say moderately, severely, slightly..?

HWM05: Moderately I think.

RB: Mmhm. So is there anything that you used to do before that you can't any more because of your Afib?

HWM05: It it's, um, I wouldn't go for a run at the moment but that could be due to.. the operation was only a month or so ago, at least that's what I'm hoping for

RB: Yeah. What is it that.. Is it that you don't feel that you've got the energy,

HWM05: Yeah…

RB: …or you're worried about feeling unwell when you're out running, what is it that stops you going for a run?

HWM05: Yeah. Well, energy's a problem

RB: Right

HWM05: My resting heart rate is as high as what my running heart rate used to be. So I don't really want to go running with a heart rate that already thinks its running

RB: Yeah ok, so are you worried about damaging you heart?

HWM05: 'Cause it was over, when I got rushed back in it was over 150

RB: Yeah

HWM05: Um so. It does like, my blood pressure dropped and I went [inaudible] so I don't really want to be out in the middle of a field somewhere and get myself into that situation really

RB: Sure, so you wouldn't want to be out somewhere alone and end up feeling sort of..

HWM05: No

RB: Yeah. And does it worry you that you might damage your heart by running when you've got a fast heart rate?

HWM05: Quite possibly. When I first asked the surgeon and things, he sort of said the benefits of running um as long as you're not sort of doing a marathon, outweighs any sort of bad effects, so.. you know exercise in moderation is perfect for it really

RB: Right, ok. But you struggle to do that really because of your symptoms?

HWM05: Yeah

RB: Yeah, ok, I understand. And then pain and discomfort, do you have any pain or discomfort because of your A, Afib?

HWM05: Um, again I didn't used to but I do now.

RB: Right. And what's that like?

HWM05: Just a null, like a null pain in my chest really, so the last time I went in they just said it's nothing to worry about.

RB: Yeah. And is that there constantly?

HWM05: Yeah

RB: Yeah. And is it a central pain or does it move around?

HWM05: Yeah central pain, just sort of off the left central in the body really, so just about where the heart is really that sort of height

RB: And how long have you had that for roughly?

HWM05: Um since the week after I had the abilation. So after I got rushed back in I had severe pain then, so since then so the last three weeks it's been pretty much there

RB: It's just been there constantly. Ok. Then moving on to the last question on that page which is about anxiety and depression – do you feel at all anxious or depressed about, about what's happening to you really?

HWM05: No, I wouldn't say I do. I'm just a little bit.. annoyed's probably not the right word to use but it's starting to get me down a little bit, yeah

RB: Yeah

HWM05: It's starting just to, starting to annoy me a little bit where it's just… If I could maybe rewind to January and not phone my doctor, I probably in a couple of days will have had.. you know my shoulder would have been better and I probably would.. at this point I feel like I'd be better off

RB: Ok, that's interesting. OK. So then on the last page of this questionnaire, there's a sort of thermometer from nought to a hundred. If nought was the worst health you could imagine, and one hundred was the best health you could imagine, where would you put yourself on that scale today?

HWM05: Probably round about 60, 65..

RB: Mmhm. And is that all because of your AF?

HWM05: Yeah

RB: You don't have any other problems with your health that are bothering you and..

HWM05 No

RB: … that would make that higher or lower or..

HWM05: No

RB: Ok. Well thanks very much for going through those, that's very helpful. So as you know this study is looking at the connection between AF and being overweight

HWM05: Yeah

RB: Before I contacted you about this study did you.. Were you at all aware that there could be a connection between those two things?

HWM05: No I was never told that

RB: No, so nobody had discussed that with you at all

HWM05: No.

RB: I think in your case possibly the fact that you've been in and out so many times it hasn't been appropriate to have a conversation with you about that. Um but I wanted, I'm just interested really in the way that people who've got AF manage their weight because obviously you've described your symptoms as being quite, you know, a lot of breathlessness and tiredness and that affecting what you can do, um and if we're going to help people with AF to manage their weight we need to know the best way of doing that. So is there anything, have you ever tried to manage your weight before in the past?

HWM05: No

RB: No. And is it ever something that's bothered you or something you've thought about?

HWM05: No. I probably I got to, I probably got to 14-and-a-half stone at my heaviest

RB: Yeah

HWM05: And thought do you know what I need to lose a stone. I just put a bit more effort in really, just doing a bit of running, a bit more walking, eating better, not eating as much, yeah, just that really, I've never had a I've never.. been quite lucky really I've never had an issue with my weight, I've always sort of… On your scales I'm probably 13 stone 9, 13 stone 10 now but I wouldn't wanna be on the lines that I should be that I think 11st10 would be my ideal weight for my height and age but I wouldn't wanna go down to that, you know, I think just 13 or just under's just about right for me really. And I wouldn't have an issue getting to that, I think I could manage that I think I could get under 13st if I wanted, if I *really* wanted to

RB: Yeah. What is it, how do you, how do you decide what's a good weight for you? What makes you say that's a good weight for you to feel?

HWM05: It's it's like a good weight, I kind of like played a lot of sport over the years, being younger and that.  I kind of knew what my weight was that my frame carries better. So I was like at my sharpest, and my quickest and I know around what weight that was. So I kind of judge it through that really. So I know, I know, I know if I lost half a stone I would feel that little bit quicker, a bit lighter, but I wouldn't want to lose any more than that because it would like take that bit of strength away

RB: Right, right, so you're prioritising strength as much as anything then?

HWM05: Yes. Strength and fitness yeah. So I wouldn't wanna… But then my job sort of demands a bit of that as well really

RB: Yeah, yeah. You've got an active job…

HWM05: You know I do come across things that are quite heavy and things, I've got to do a bit of lifting…

RB: Yeah, so now obviously you're struggling a bit with doing as much exercise as you used to, if you were to start putting weight on and you were struggling to get it off again, would you want any medical advice or would you want any particular services to help you deal with that?

HWM05: I don't think so, I'd probably try and manage it with food

RB Sure. And how would you do that, how would you do that with your food?

HWM05: Um I'd eat less, less rubbish, less fatty contents, maybe a bit more fruit and things, try and put a bit more fibre in my diet. So I'd be able to manage, I mean we all like dunking a biscuit in our tea don't we? But you know I could live without it as well.

RB: Yeah [laughing]. And within your family is it easy to change what you eat?

HWM05: Um yeah, that wouldn't be a problem, we do tend to eat fairly healthy. I'm not saying we're vegans and live off plants..

RB: That's not necessarily healthy

HWM05: ..but yeah in general we kind of cook and eat fresh food, we don't eat rubbish

RB: Yeah, and you all eat together and you wouldn't have any difficulty..

HWM05: No no, we all eat as a family and stuff, yeah

RB: Um thinking about exercise as a way of controlling weight, you mentioned that you would feel anxious about going out for a run in case you felt unwell – would you want  any services, would any services be beneficial to you where you could do exercise but not be on your own, like a gym?

HWM05: Yeah, yeah quite possibly, I might feel a bit better, certainly at this moment in time I would feel a bit better inside you know maybe on a running machine as against running out on a field

RB: Yeah. It's a bit difficult to go to the gym at the moment anyway with coronavirus but do you have the opportunity to go to the gym? Do you…

HWM05: I could, I mean I haven't been to a gym for a number of years because I don't really feel I need to go to a gym 'cause I've got quite a physical job, so I just kind of get… and then if.. if I I feel better and I start doing a bit of running again, I mean I'm not going to be running marathons at my age, you know if I can run [in background wife says "play golf"] sort of 3 or 5 kilometres, and I play golf so I'm not a couch potato sat around

RB: No no, you're pretty active. Yeah. I'm not, just to be clear as well I'm not suggesting that you ought to do any of these things it's just to understand what people want

HWM05: No I'm just clarifying that it's not , you know I'm not sat around, so yeah a gym would be beneficial but I would be able to manage it by taking the dog and walking the dog further and that, but at this moment in time I wouldn't – walking the dog I'd feel ok about but I'm not sure about running or..

RB: Sure.

HWM05: And I'm not sure I'd have the energy for that

RB: No ok. And do you feel like you have time to do weight management things like managing your diet and doing exercise, do you manage to fit that into your daily routine alright?

HWM05: I can do that, I'm not one for eating in the day, you know, a lot of people probably tell you it's not good for you but I'm quite happy not to eat from.. until I get home after work. Not every day but um, most of the time I won't eat during the day but I will eat a good meal at night, so yeah. I've not got a problem with sort of managing food really.

RB: Yeah. It just doesn't sort of bother you

HWM05: It no, I'm not that bothered by it.

RB: And when you're thinking about managing your weight, you mentioned when you went up to 14st you thought "oh I ought to lose a stone there", what is it that motivates you to do that?

HWM05: Well I got up to about 14 and a half, so.. and I could tell by you know putting new jeans on and stuff that.. you need another button. Um and then sort of walk past a mirror and think oh god who's that fat bloke in the mirror, and then I thought do you know what, I need to lose, I need to lose a little bit of weight really.

RB: Yeah. So it was the fit of your clothes and seeing yourself in the mirror?

HWM05: Yeah, and I knew sort of consciously that I was going the wrong way rather than, it weren't, it were slowly going up rather than levelling off. So I a def.. don't want to be, so I was quite happy to try and do something about it really

RB: Sure, nip it in the bud.

HWM05: Yeah. Well I think from when they found out I had Afib to when I had the ablation I think I lost nearly a stone, so

RB: That's a lot.

HWM05: Yeah

RB: Good. That's all my questions about managing weight so that's really helpful thank you. I'm just going to ask you a couple of questions, more technical questions if that's alright

HWM05: Yeah

RB: So ethnicity, how do you describe yourself ethnically?

HWM05: I'm white British.

RB: White British. And you mentioned that you're a bathroom fitter?

HWM05: Yeah

RB: What's the highest level of education that you had?

HWM05: Um just school really

RB: School, yeah, secondary school?

HWM05: Yeah

RB: You didn't go on to college or anything like that?

HWM05: No.

RB: No, that's fine. And the, mentioned that you went up to 14.5 stone, how tall are you?

HWM05: Um 5'9, 5'10

RB: And what do you weigh at the moment?

HWM05: Um, without getting on the scales I'd say about 13st10

RB: 13st10, uh-huh. And then my very last question is one that usually makes people laugh quite a lot. I haven't decided yet whether I'm going to use numbers to identify people in this study or if to give people pseudonyms. If I was to give you a pseudonym what would you want to be called?

HWM05: Um, Jay?

RB: Jay, that would be absolutely fine. So if I published a paper in a medical journal and referred to somebody called Jay, would you be happy with that?

HWM05: I wouldn't have a problem with that.

RB: Lovely thank you ever so much. So, do you have anything else that you wanted to mention, anything that you think you would want clinicians to know about helping people manage AF or manage their weight?

HWM05: No, not really, 'cause I kind of don't know enough about it myself you know?

RB: Right

HWM05: I've kind of only sort of had this issue since January and it's all sort of – never heard of it before, so it sort of took me a little while to sort of get some information in for myself really, to find out what that was an what was going.. and the best way to sort of try and tackle that really so there's never really been an issue about.. my weight was never really an issue

RB: No ok

HWM05: So I'm not really accounting AF with a weight problem

RB: No I understand. Do you feel like you would have… just leaving the weight aside in terms of when you were diagnosed with AF back in January, would you have wanted more information about that or any particular service or sort of patient focus group of anything that would have helped you learn about it?

HWM05: I can't – to be fair to the cardiology team at the [hospital name], they were very informative. But if there's ways and things that can improve, um, yeah of course you'd want to know about them straight away wouldn't you? You know if it's an improvement in your diet that can improve your health your AF better then yeah, why not? That's the sort of information they should be feeding you straight away really.

RB: Sure so as much as like wanting tablets or wanting you know, not necessarily *wanting* tablets, but you know wanting good medical management you'd want to know about lifestyle changes that you could potentially think about

HWM05: Yeah absolutely I'm all for that, you know and I know the medical side don't really associate with that too much but, I'm all for that. You know if you give me a banana or a tablet and say you've got to have one of them a day, I'd take the banana [RB laughs] so if they're both doing the same thing I'd definitely have the banana

RB: Right! Alright! I'll see if I can get your bananas on prescription then shall I?

HWM05: Yeah that'd be nice. It's probably cheaper buying them in the supermarket with the price of prescriptions

RB: Yeah you can get quite a lot of bananas for 7 quid

HWM05: Nine pound 15

RB: Is it £9 now? Blimey

HWM05: Yeah £9.15.

RB: Yeah that's a lot of bananas

HWM05: Yeah, per item that as well so I've got three lots of tablets so that's best part of 30 quid every time I go in the chemist.

RB: Yeah, it adds up doesn't it?

HWM05: It's a lot of bananas yeah.

RB: It's a lot of bananas.

HWM05: I'd be making banana cakes and all sorts, that wouldn't be good for my weight would it?

RB: Yeah just stick to the plain bananas I'm afraid. [Name] thanks so much for doing this it's really been very interesting. Um what will happen now is that as I said I'll type this interview up and then in about 10 days to two weeks time I'll give you a call

HWM05: No problem

RB: And just read back what I've got from the interview so that you can check it for me and let me know if I've you know got the gist or.. And if there's anything else that you want to add or that comes to mind feel free to say or drop me an email or call me on that number which is all in that information a sheet. And I'll send you the information sheet out in the post to get a written copy as well

HWM05: Yeah, I'll pop that back to you straight away

RB: Alright thanks so much, have a nice evening.

HWM05: Yeah you too, bye bye

RB: Cheers, bye.

[END]