HWM03 19Oct20 interview transcript

RB: So [name] thanks very much for agreeing to take part in this study.
HWM03: That's fine, my love
RB: Um, because we've never met and I don't know, I don't know you at all, can you tell me a little bit about yourself just to start off with? And particularly about your atrial fibrillation, how.. how did that start and um..
HWM03: Well it first, it first started about.. Well I had, I'd been at work one day - it was about 16 years ago - and I'd got home from work, I'd eaten my dinner, and I'd gone to bed and um just my heart was just started, it was just going absolutely mad and I was sick and it was awful so my then partner called an ambulance and they took me to hospital and then, at the time, they called it.. What was it they called it? Some holiday syndrome or something like that and they told me it you sit on something cold it should help it so well I'd never heard of that so they sat me on this cold commode [both laugh] That didn't help and then I don't know what they done they gave me an injection or something and it wasn't too bad so I went home and I kind of, all sort of through the years used to keep getting these funny heart flutterings all the time and like my heart would it felt like my heart stopped beating and then beated really hard - I know it hadn't stopped beating, if not I wouldn't be here - but it felt like it had stopped and then like a horse had kicked me in the chest and it started again and that happened for a few years and I first saw the consultant about 15 years ago and um he just said oh it was probably just me just my heart and I maybe needed a pacemaker or something and I went back a few times and it had settled down then so they put me off they said fine ok and then about 3 years ago it all came 2, 3 years ago it started with a vengeance again one day I was here and I had to call an ambulance at 5:30 in the morning because I was really bad I was sick I was dizzy, like I was gonna pass out so the ambulance took me to hospital and they gave me some tablets to stop it and then I had to go and have an echo and then they sent me home but they sent me to the heart specialist and they put me on betablockers um then when I was at work I had a really bad one and they called an ambulance took me to hospital again and that's when they decided that I'd got AF and I saw the specialist again and not just the betablockers they put me on flecainide, blood thinners, and also statins although they said that my cholesterol was fine but with they fact that this AF had started to get really bad so they put me on all those tablets. Um then I had to go back to the hospital last year and they were going to do the ablation in February but I had to stop taking my tablets for a week and I said to them I can't do that because I work, and couldn't get the time off work and I still have the breakthroughs even with taking the tablets so I have to take more tablets so they decided um not to do it, but then it still kept on and even with the tablets and the last time um the specialist phoned me I was taking far more flecainide than I should have done, because he said to me it's not good you taking all those but I said it just won't stop so that's when he said alright the ablation you need to have the ablation and I said to him but if I stop taking the tablets I can't have a week off work before the ablation so he said to me alright just carry on taking the tablets because as you live alone I don't want you passing out and there's nobody there so that's when we decided for the ablation and it came through really quick and I had the ablation on the 2nd of October, so..
RB: Mmhm, brilliant
HWM03: but.. At the minute touch wood it feels like it wants to start, like at work today it kind of skipped a beat and I thought oh no please don't start because they said if it starts again then I'll have to have it done' again um and I wasn't too brilliant after I had it done I had a lot of pain in my chest and I couldn't breathe, I could only walk three steps and I was totally out of breath I stayed at [daughter]'s for a few days before I came home er they gave me codeine for the p.. In wasn't a pain in my chest I just couldn't lay down, and when I lay down it felt like there was somebody laying on my chest um and my doctor who I spoke to got in touch with the surgeon who done it and he said that it may have been is there a sack or something around your heart?
RB That's right

HWM03: He said it could be that because I was bruised inside because also they gave me a general anaesthetic um and he said it could have been that, or it could have been they put a camera down don't they to look at your heart to make sure there's no blood clots or anything but that actually since they gave me I mean the doctor gave me codeine um for the pain um and actually now I'm pretty much back to normal, I went to work on Saturday and I worked Saturday, yesterday, today and tomorrow and Wednesday so at the minute as I say apart from I thought it was going to start today just a little flutter but they did say I may experience palpitations for up to three months so I'm just hoping that it has settled down now. Um they've taken me off flecainide and they've also taken me off the beta-blocker um I am a bit concerned really about being off the beta-blockers because my heart was steady at 70 beats a minute, I've got my own pressure cuff to take my blood pressure and it takes my heart rate and my heart rate has now gone up to 94 um I don't know, and I can feel it, and I can hear it beating in my ears beating, but I don't know if that's normal after you've had the ablation or if it's just what my heart, because I'm now off the beta-blockers, is now doing. Because I presume the beta-blockers kept it at a steady 70 but now I'm not on them it's gone up to 94 and it was 103 the other day [laughs] so yeah, but um, at the minute like I say it's seems to be alright at the minute.
RB: Ok. Wow. You've been, er had quite a journey with your AF haven't you?
HWM03: Just a bit! [both laugh]
RB: Thank you for all that. I'm going to start going through the questionnaires now with you, if that's ok.
HWM03: Yeah, that's fine
RB: So the first one we're going to look at is the one that says University of Toronto Atrial Fibrillation Severity Score at the top
HWM03: Yep
RB: Yeah?
HWM03: Yeah I've got that
RB: Lovely. So part 1a Sex, I've put female. Is that right?
HWM03: Yeah [laughs]
RB: We don't need your whole date of birth, but can I put the year of your birth down?
HWM03: Yeah, it's 1958
RB: 1958, lovely. And from what you've said, question 3 Are you in Atrial Fibrillation currently? It sounds like that a..
HWM03: No
RB: No. Good. [Name] I'm really sorry the dog's decided he needs to go out. I'll be one second.
HWM03: That's alright. Don't worry
RB: [speaks to dog]. Now he's decided he's stopping in. Door's open if he decides to go out
HWM03: [laughs]
RB: Honestly. Now question 4 is how do you feel about your life at the present time?
HWM03: Yeah, well I don't, I'm not in atrial fibrillation so fine
RB: Good so if you had to choose a score from 1 to 10 where 1 was your worst possible life and 10 was the best possible
HWM03: 8
RB: Oh that's pretty good! Lovely, ok. So I know that you've just had your ablation so obviously this is a bit different…
HWM03: Yeah
RB: …but when you were having your atrial fibrillation, how often were you having it?
HWM03: Oh pretty much every day
RB: And was that continuously every day, or…
HWM03: No, it would just started at periodic times, maybe a couple of times a day. Sometimes, some weeks it wasn't every day. Um it was you know, so weeks I could go without having any but then it would start again with a vengeance.
RB: Right
HWM03: So, maybe 4 to 5 times a week most likely

RB: Right, and then you'd have these periods where you weren't having it?
HWM03: Yeah
RB: Ok. Then on average how long would the episodes last when you were having one?
HWM03: Several hours but less than a day. They would go on for a few hours.
RB: So you'd have some periods everyday where you weren't in fibrillation?
HWM03: Yeah
RB: And most recently, just before you had your ablation, um how severe was your last episode before you had your ablation, from 1 to 10?
HWM03: Um, oh gosh, that was probably about a 9.
RB: Oh gosh, that's a… It must have been quite debilitating for you, was it?
HWM03: Yeah. And it's frightening as well, especially when you live alone now.
RB: Yeah, yeah. And then the first episode you ever had, that was sixteen years ago you said, in bed
HWM03: Yeah and that was bad. That was really bad. That must have been a ten I should think that because I was sick and everything, that was really bad
RB: It sounds horrible. It must have been very frightening
HWM03: It is.
RB: Then we're looking on at part b now and what treatment you've had. Did you ever have a cardioversion - that's an electric shock - to try and get you into rhythm?
HWM03: No.
RB: And how many times in the last year have you had to go into A&E because of your atrial fibrillation?
HWM03: Er, twice
RB: Twice in the last year. And were there any other times apart from those two that you were hospitalised?
HWM03: [counting] Um one.. Two.. actually I've been in, not stayed in hospital but I've actually been in hospital one, two I think three if not four times. But I wasn't kept in.
RB: And that was always because of your atrial fibrillation?
HWM03: Yeah it was
RB: And how many times have you seen your cardiologist in the last year because of your heart rhythm?
HWM03: Er, twice.
RB: And that's including when you saw him about the, having the ablation done?
HWM03: Oh no that was three then because he phoned me that time because of COVID
RB: Because of blinking COVID
HWM03: Yeah.
RB: Ok. Now we're going on to part C which is how bothersome your symptoms are and we're talking in the last 4 weeks
HWM03: Right
RB: So I realise you had your ablation so it's going to be a bit different…
HWM03: Well in the last four weeks um, it was quite a lot before I had the ablation
RB: It was quite a bad, yeah?
HWM03: Yeah
RB: So um, how would you rate yourself on this scale, How often have you been bothered by this symptom over the past four weeks?
HWM03: A fair amount, I would say
RB: A fair amount. And then when you're at rest do you ever feel short of breath.
HWM03: No
RB: So when you have your atrial fibrillation you don't feel breathless
HWM03: Not, not really, I get, to be honest I get breathless because I'm panicking
RB: Ok, but it's not the, the beating of your heart doesn't make you feel breathless?
HWM03: No, no.
RB: So would you say 'I've not had this symptom in the past four weeks'?
HWM03: Yeah

RB: Shortness of breath during physical activity, if you're having to you know, put the Hoover round or if you were running for a bus would you get short of breath?
HWM03: Er, probably running for a bus I would 'cause I'm not good at running [laughs] but just just little, just doing normal everyday things no
RB: and can you carry on doing normal every day things when you've got your atrial fibrillation?
HWM03: Erm… Not really no. It kind of.. It slows me down a bit.
RB: Ok. So looking at that question would you say - so this is shortness of breath during physical activity - would you say very little, or a little?
HWM03: A little.
RB: A little. And then do you get tired when you're doing physical activity?
HWM03: Not really
RB: And what about when you're sitting down resting, do you feel tired then?
HWM03: No
RB: And then dizziness and lightheadedness you've spoken about a bit - has that been troublesome to you?
HWM03: That I get that a lot when I go into real full-blown stuff I get it [phone vibrates] It's alright it's my daughter trying to phone me, she can phone me back [laughs]. Yeah a lot, like I used to get lightheaded and dizzy a lot.
RB: Ok. And then chest pain or pressure, you mentioned you had some chest pain after the ablation
HWM03: Yeah. But I don't think that was such a pain it was just like I said [phone vibrates] uh, she's text me now… like I said when I was sitting and breathing it was hurting me but when I lay down it was bad it was really bad but that was just after the ablation and I'm cer.. I'm pretty certain that I was just sore from that.
RB: I think so, yeah. You don't think it was anything to do with your heart beat?
HWM03: I don't think so, no, I don't think so.
RB: So what would you say on there, would you say a lot because of the ablation or would you say you haven't had it because you don't think it was to do with your heart?
HWM03: No, I've said that I haven't had it because it wasn't, it was just the ablation.
RB: Yeah. That's lovely. Ok, so we'll have a look at the other questionnaire now, the one that says EQ-5D-5L on it.
HWM03: Yeah
RB: This is, this is less questions and less specific
HWM03: [laughs] Right, yeah I've got that.
RB: So the first one, mobility, can you have a look at those answers there and let me know what you think?
HWM03: Yeah I've got no trouble walking about
RB: … no trouble walking about.
HWM03: No, I've got no problems washing or dressing myself, No problems doing my usual activities, I've got no pain or discomfort at the minute. Um I have been diagnosed as with depression and anxiety
RB: Mmhm
HWM03: And I take tablets for that, I take venlafaxine. So I suppose, slightly.. I don't know, slightly anxious or depressed?
RB: How do you feel? Apart from the tablets you're taking that obviously help you, how do you feel in yourself?
HWM03: Yeah no I'm fine
RB: You don't feel anxious or depressed
HWM03: Not at the minute, no
RB: So you'd be more saying that you felt anxious or depressed to say that you've got a diagnosis but that you're not feeling it at the moment?
HWM03: Yeah no I'm not, no.
RB: And then you've got this sort of thermometer on the other side, from nought to a hundred

HWM03: Yep
RB: If nought was the worst health you could imagine, and one hundred was the best health you can imagine, what score would you give yourself on there?
HWM03: Oh I should think 90 today
RB: Good! Feeling good! Lovely, thank you for filling those in with me
HWM03: that's alright m'love
RB: We'll refer back to them as we go through the interview. I'm sorry I'm having a computer issue here
HWM03: That's alright!
RB: I'll sort that out afterwards. So going back through those questions
HWM03: Yeah
RB: You've said you had no problems with walking about, no problems with personal care.
HWM03: No
RB: Do you feel like you can do absolutely everything you want to?
HWM03: Yeah I can now I can, I can't run but then I never could [laughs]
RB: But you mentioned that when you were in atrial fibrillation it would slow you down, would that affect..
HWM03: Yeah, it would. That would affect my day to day life. I mean if I was at work I used to try to carry on the best I could, sometimes I used to have to sit down and then I'd take extra tablets, um, so I suppose it slowed me down a little bit because I was more anxious then that I was going to pass out
RB: Sure, that's understandable. And you said you didn't have any pain or discomfort, um, did the atrial fibrillation cause you any discomfort at all?
HWM03: No, no pain, it was just the um the rapid heartbeat that felt like it was bursting out my heart felt like it was coming out my chest
RB: Which must have been quite, caused you quite, um, did that cause you anxiety when it felt like that?
HWM03: Yeah it did
RB: So now you haven't got that sensation and you're not feeling anxious, that's great. But when it was going on that increased your levels of anxiety do you think?
HWM03: Yeah ever so much
RB: And did you ever limit what you did because of that anxiety that it caused you?
HWM03: Well yeah I used to.. I was frightened to do some things especially if I was at home in case I passed out so I just used to sit down when I was at home
RB: Yeah, just to keep safe?
HWM03: Yeah
RB: And what um, when you went to see the specialists about your atrial fibrillation, what sort of advice did they give you about managing your symptoms?
HWM03: Well, just tablets really. You know there was no reason they gave, there is no sort of I suppose no reason why it sort of just started I mean my heart was fine because I've had an echo um all sorts, and from that they said my heart looked absolutely fine,
RB: Mmhm
HWM03: And there was nothing that they could actually see that was wrong with my heart um but it just obviously, because I've got so many heart problems in the family um, most of them have all died from heart attacks and like I say my mum's had four, um.. and um.. so I presume... it, it was just that and they couldn't tell why it suddenly starts like it does because I could just be sitting down and it starts or I could be in the bath and it could start, I could be at work and it could start so they just, that's when they gave me the other tablets the flecainide, and that I had to take to try and keep it at bay and then if I did get breakthrough episodes I'd just have to take another tablet
RB: Right, yeah, right, I've got you. And so they never talked to you about things you could do to improve your symptoms?
HWM03: No
RB: That's fine. So moving on a little bit to your weight, you mentioned you lost quite a lot of weight recently, I think you said because of irritable bowel syndrome?

HWM03: It's inflammatory bowel disease
RB: Inflammatory bowel disease, ok. So when did you start with that?
HWM03: Oh crikey, this, that started last year, last March?
RB: Right, March this year that's just
HWM03: No last year
RB: So 19.. 2019?
HWM03: Yeah. And I've seen the specialist, one, two, three times so far, and I've another appointment to go back, I think it's December?
RB: Right. And how, can I ask how much weight you've lost because of that?
HWM03: Well, I lost.. I wa.. Years ago I did weight 13 stone after I had my last child I was 42 when I had my last daughter
RB: Yeah
HWM03: Er, and I gained a lot of weight and also I used to drink quite a lot of alcohol, I mean I haven't drunk alcohol for 18 months because I used to find that if I did drink alcohol that could start off my AF, so I just stopped drinking alcohol. My partner and I separated, I lost a lot of weight, and since I've had the bowel thing I lost about another stone, so now I'm down to about, I weigh about 9 stone 10 now
RB: Ok. And how do you feel at the moment?
HWM03: Yeah, not too bad thank you
RB: And can I just ask how tall you are as well, [name]?
HWM03: 5 foot 2
RB: Ok. So when you were, mentioned you were 13 stone, that is a bit overweight for 5'2
HWM03: Yeah, definitely
RB: How did you feel about your weight?
HWM03: I hated it. I did I hated being so big I'd never been that big. Well I mean as a child I was fat, I was a fat child, um and I lost a lot of weight when I was 16
RB: Mmhm
HWM03: And I lost all the weight from having my three elder children but then when I had my last child I found it really difficult to lose, ehm [phone vibrates] it's alright it's [daughter] again [laughs]. But then, em, like I say when my partner and I separated I lost a lot of weight then and when I stopped drinking wine um altogether I lost even more
RB: Yeah, ok. When you were overweight, what was it about being overweight that bothered you?
HWM03: I just didn't like being overweight.
RB: Was it because of the way you looked or..
HWM03: Yeah it was
RB: ...or because you found it limiting?
HWM03: Yeah, the way I looked
RB: Sure, ok. Um, and now do you feel happy with the way you look?
HWM03: Yeah I'm happ.., I'm a lot happier with the weight and everything and the way I am
RB: Mmhm, yeah. When you were overweight and you would go to your GP or a doctor, did they ever talk to you about your weight?
HWM03: Not really no. They did say that my BMI was high
RB: Mmhm
HWM03: And that it really shouldn't be that high it should be lower, but then, um, as again, as I started losing it and funnily enough last year I had to go and see a doctor and she looked at me and she said "Good grief Mrs [surname], you've lost a lot of weight!" [both laugh] and I went "yes I have!". She said "Yes", she said "Good grief it suits you" and she took down my BMI she said that my BMI was fine I said "oh thank you"
RB: [laughing] shame you had to go through inflammatory bowel disease to get there
HWM03: Yeah [laughs]
RB: So they never mentioned to you.. And what about cardiologists, when you went to the cardiologists, bearing in mind your family history, did any of them talk about your weight at all?

HWM03: No. Because by the time I'd actually gone to see the other specialist, when I went years ago they didn't mention my weight. So when I started seeing the specialist a couple of years ago, um, my weight, I'd already lost it, I was down to you know, what I am now.
RB: Yeah. But prior to that nobody had talked to you, none of the doctors you'd seen had talked to you about your weight
HWM03: No, no.
RB: Ok. When you were 16 and after you had your first three children, how did you go about losing the weight?
HWM03: Well I lived in America, my ex-husband is American, [daughter] was born in America at an air-force base there and I just, I just ate healthy I suppose and it just came off. It was very hot out there and used to walk a lot because I didn't like driving out there so I used to walk quite a lot as well.
RB: But that didn't work for you after you had your last child?
HWM03: No.
RB: What do you think changed?
HWM03: No, well I was with a different partner, my youngest daughter has got a different dad to the eldest three, and I was quite unhappy and I think the drinking didn't help my weight, the wine drinking that I used to drink at night, just didn't help
RB: Sure, yeah. And you were drinking the wine because you were unhappy?
HWM03: Yeah
RB: Yeah, that's understandable. And if you had.. Did you ever seek any help from doctors to manage your weight at all?
HWM03: No. When I was younger I did. When I was about 8 or 9 I was put on a diet by a doctor, because I was really big.
RB: Yeah. So you weight's fluctuated quite a bit over the years hasn't it?
HWM03: Yeah it has, it has
RB: What kind of diet did the doctor put you on when you were 8?
HWM03: Oh goodness me I can't remember, I know it was obviously no chocolate, crisps and things like that. I had a grandma who lived in the kind of old time and we lived next door to each other and she used to make lots of apple pies and things like that so obviously I wasn't allowed to eat those, there was no kind of sweets or any kind of thing like that, none of that, it was just whatever was cooked, um, like things like years ago it was just things like meat and potatoes, and vegetables, shepherd's pie and things like that. So really basically it was cutting out all the sweet stuff that my nan used to make and buy for me.
RB: Mmhm, ok so you, do you think, did you put on weight, did you get fat because your gran was buying you sweets and things?
HWM03: Probably
RB: You mentioned you're an only child, do you think that affected it?
HWM03: Yeah most likely, it was, I don't know really. My childhood wasn't brilliant so I won't go into that but my childhood was awful really, um, and um I think probably I just used to eat 'cause I was unhappy. It was either eating 'cause I was unhappy or when I was older drinking 'cause I was unhappy.
RB: Aw. So you'd go and seek comfort
HWM03: Yeah
RB: Ok. If a doctor had talked to you about weight when you were overweight and unhappy about your weight, what sort of services would you have wanted? What would have been appealing to you to help you?
HWM03: I don't know really. Years ago when I lived in [city] um, they could, sounds silly I know but they could put the gym on prescription for so many months, which is what one doctor done for me and I used to go to the gym, um, oh two, three times a week then..
RB: Right
HWM03: ..and do obviously everything, treadmill and everything the bikes and things like that, that was goodness years and years ago when I was in my 30s
RB: But you did that, when it was prescribed by the doctor you went along and did that
HWM03: Yeah

RB: Yeah. And would you still do that now? I mean I know that you don't particularly need to lose weight at the moment but if you were to put weight on and the doctor said oh I'll prescribe the gym, is that something that would appeal to you?
HWM03: Well yeah, I would go
RB: Do you do quite a lot of physical exercise?
HWM03: Not really, I mean where I work I work for [national supermarket chain] I'm upstairs in the kitchen, I'm a cook up there. But there is a lot of walking, I couldn't count how many steps I do, in fact today when I came home my feet were aching so bad I worked 7 til half past two with just my 15 minute break, so I pretty much I was quite tired today when I came home 'cause I was quite busy, and there is quite a lot to do there. But if not on a day off or something when I've done my housework and that I go for a walk, um, I'd go swimming because the heart specialist actually did tell me to go swimming but to be honest I don't like going alone and one of my sons, my youngest son his girlfriend likes swimming and we were going to go together but she's a veterinary nurse so it's her shifts don't kind of coincide with mine
RB: Yeah, mmhm, what is it that, why don't you like going on you own?
HWM03: I dunno really, I'm just a bit well I don't know if it's a bit self conscious or what, I don't know. I just think it's nice to go with somebody else that you can you know swim with and talk to
RB: Yeah, you like the company
HWM03: Yeah
RB: Ok. And then, as you know this study that I'm doing is about the link between atrial fibrillation and weight..
HWM03: Yeah
RB: ..did you know that there was a connection between atrial fibrillation and weight before I sent..
HWM03: No
RB: ..you that information sheet? Nobody had ever told you about that?
HWM03: No
RB: I suppose when you went to see the consultant about having your ablation you'd already lost the weight
HWM03: Yeah I had
RB: But prior to that nobody'd ever mentioned it?
HWM03: No
RB: Knowing that now, would that affect how you would feel if you started to put weight on again?
HWM03: It would
RB: And would you want any services in particular to deal with that?
HWM03: Well know I mean obviously I try to keep my weight down I don't eat kind of swe.. I do occasionally have something sweet and I don't go out to just eat salads and things normally but if I find that I've put on a couple of pounds then I'll just not eat the sweet stuff I just stop eating it until my weight goes back
RB: That's so that's how you would manage your weight, just by managing your diet
HWM03: Yeah
RB: Sure. That's absolutely brilliant. [Name] that's all my questions answered, oh I've just got a few more just technical ones if you don't mind
HWM03: Yeah that's fine
RB: Um How many years, what what age did you leave school at?
HWM03: 16
RB: 16. So secondary school?
HWM03: Yeah.
RB: And how would you - sorry these are technical questions we always ask you at the hospital - how would you describe your ethnicity?
HWM03: White British
RB: White British. And you said you're a cook at [supermarket], in the cafe is that

HWM03: [phone vibrating] sorry it's [daughter] again
RB: [laughs] You said you're a cook at [supermarket]
HWM03: Yep
RB: How long have you done that?
HWM03: 6 years [gives exact date]
RB: Oh! Coming up for your anniversary! Do you enjoy it?
HWM03: Yeah I do actually
RB: It's a good job yeah?
HWM03 Yeah, I've got another 4 years before I retire so if I'm still there then that'll be my tenth year when I retire
RB: Ah, that'll be a party! [both laugh] Lovely. [Name] thank you. Oh One more thing that's very important, I have decided yet whether I'm going to use numbers for people or false names. If I was to give you a false name, what would you like to be called?
HWM03: Oh crikey I don't know, you can think of something
RB: Ok, there's no name you really hate and would say don't call me that
HWM03: No, no oh I honestly don't know.
RB: If you had another daughter what would you call her?
HWM03: Oh good grief I don't know that either! [laughing] I'm not very helpful am I?.
RB: No problem
HWM03 Just put Jane, I don't know
RB: Jane, that's a very good name, that'll do nicely. [Name] thank you ever so much for your time today - is there anything else that you wanted to talk about?
HWM03 No, I think that's it
RB Lovely, well you've been really helpful, it's been ever so interesting talking to you.

[END]