HWM02 Interview Transcript 01-Oct-2020

RB: Ok so the first thing I was going to go through with you was these questionnaires which I think you've done before..
HWM02: Ok
RB: ...or you might not have done, actually, because I don't think we use these ones on [name of other research study] actually, but this one's about your atrial fibrillation symptoms and the other one's about quality of life so it's just quite interesting to get a feeling of how much your atrial fibrillation's affecting what you can do and what you can't do. So if I give you that... As you go through it you don't have to fill in every question if you don't want to put your date of birth or you don't want to answer certain questions that's alright, but just speak to me as you're doing it because I'm interested in what you're thinking. [Long pause] So you're male we know that… [long pause] So this question's "Are you atrial fibrillation currently?". Do you feel when you're in atrial fibrillation? [pause]
HWM02: [reading] "How do you feel about your life at the present time?". I'm alright. Very good. "How often" [Inaudible] Oh… (sighs) Two or three times a week I would say.
RB: You feel it when you're in?
HWM02: Yeah
RB: Yeah?
HWM02: Yeah, definitely. I know my when pulse, because I can hear it in my ears. And so when it's out of rhythm it'll go bum, bum, and then miss a beat or whatever. Yeah.
RB: Yeah. Does it bother you?
HWM02: It bothers me.. not the actual.. It bothers me that I can hear it in my ears more than anything. [Reads] "How long.. Day…" [inaudible] "several hours". Several hours. Anything else?
RB: Yes, it goes on...
HWM02: Oh dear! (laughs) It goes on...
RB: The next one's "How severe was your most recent episode?"
HWM02: "How severe… [inaudible] ...your first episode?"
RB: Can you remember the first time you had AF?
HWM02: Not really.
RB: How did you come to be diagnosed with it?
HWM02: Well I was in the doctors surgery for a blood test, and the nurse that was doing the blood test she said "You look very pale". So she got the doctor, and she just went over [places two fingers on own wrist in demonstration] and she said "Oh yeah you've got AF".
RB: But you didn't feel strange, it was she... it was the nurse who noticed you looked pale?
HWM02: Just very pale so… [inaudible] well I didn't really feel it much. "Have you ever been… [pause] I don't think I've been there any time, to the hospital
RB: To the hospital. So you've never had to come into hospital because of your AF?
HWM02: No
RB: It's never brought you in? What brings you in? Because you've been in recently haven't you? What is it that…
HWM02: It's my kidneys
RB: Your kidneys

HWM02: I mean I went in twice. I went in the first time and I don't remember… I went in that place next to A&E called AEU or something like that
RB: Yeah AEU. EAU.
HWM02: And I don't remember a thing about that, and I was in there four hours
RB: Really?
HWM02: And then the next thing I remember was being whizzed through A&E to ICU
RB: Yeah
HWM02: And I went on dialysis, And I remember very little in there - I thought the dialysis machine was made of wood.
RB: Really?
HWM02: Really. Yeah, so strange. I thought it was all a dream when I came out. So how many times did you... No, nothing. "How many times were you hospitalised in the past year for irregular heart…" well it's the same isn't it? No?
RB: Yeah, if that's what you think
HWM02: No.. "How many times have you been hospitalised in the past year because of…"
RB: Well this is how many times you've had to come in to the emergency department
HWM02: Right. And this was hospitalisations…
RB: ...it's separate hospitalisations because of your AF
HWM02: No
RB: None
HWM02: "And how many times did you visit the specialist in the past…" Well I would say, "How many times have…" it's when I go to the heart clinic only I suppose, which is once a year
RB: Mmhm, once a year [pause] Do you see the arrhythmia nurses?
HWM02: No
RB No. You see a consultant?
HWM02 I see [name of consultant]. But for some reason this year I'm not seeing him. So what do I put here then? 2, 3, 5, no idea. "How many times do you see a specialist…". Once. More?
RB: Yeah, just flip him over, there we go
HWM02: "How often have you been bothered by symptoms.. in the past four weeks?".. [inaudible] Shortness of breath, definitely [pause]
RB: Do you feel more short of breath when you've got your atrial fibrillation?
HWM02: Oh yeah
RB: Yeah
HWM02: "How often have you been bothered by the symptoms…" ...don't really bother me that much to be honest. [long pause]. More? Yes. No!
RB: No - you've done it (laughs)
HWM02: There you go
RB: And then this - this is only a short one, you'll be alright with this one. I think you've done this one before, this is the quality of life questionnaire…
HWM02: Oh yeah, definitely. Definitely. [inaudible]
RB: So you can you walk about as much as you want to?
HWM02: Yeah
RB: Yeah
HWM02: Since I've been in, and they've sorted me out, yeah. And no problems washing, no. Ah. Usual activities. Well I would be out in the shed making pens normally but I haven't done it for a long time 'cause I haven't felt like it really.
RB: I've still got my pen you made me
HWM02: Have you? Is it still working?
RB: Yeah yeah

HWM02: ‘Cause I can get you a refill
RB: Yeah no, it’s still working
HWM02: You just pull it apart from here
RB: and then you can put a refill in it?
HWM02: and twist it apart and put a refill in it
RB: Oh that’s lovely
HWM02: So if you run out let me know… “I have no pain or discomfort”... Well I do actually but only in my feet - does that count?
RB: Of course it does. It all counts.
HWM02: I have severe pain and discomfort, *extreme* pain and discomfort.
RB: Does that affect your walking about?
HWM02: Oh it wrecks. It’s the worst thing you can have.
RB: Mm
HWM02: I had it at six o’clock this morning
RB: What is it, is it gout?
HWM02: No it’s… neurothapy
RB: Oh ok, from your diabetes?
HWM02: Yeah. I did have gout in my knee last week, and that stops me walking about. But this neurothapy, it’s *horrendous*. Six o’clock this morning. I had to get up because there’s no point in laying there. Take your mind off it and get up. Like. I’m not depressed perhaps [in response to questionnaire]. Oh yes, here we go, 80 [score on QoL 0-100 scale]
RB: 80 today!
HWM02: Yeah I feel good today
RB: Oh that’s good. Thank you [name] for doing those.
HWM02: No problem
RB: Ok. So it sounds like although you’re aware of your atrial fibrillation it doesn’t...
HWM02: It doesn’t limit me too much, no
RB: ...limit what you do, but do you feel like your other medical problems - like your neuropathy - limit what you can do?
HWM02: Yeah, to a certain extent. Er, I used to be short of breath, but I don’t really get that much now because everything’s just right at the moment
RB: That’s good, you’re in a good place
HWM02: The only, the only thing is they stopped my beta-blocker, but the doctor I just seen said you can go back on it but if your blood pressure drops below 110, go back on it again
RB: Yeah, ok
HWM02: So I’m going to go back on it, because my heart rate is between 90 and 100 and to me that’s too much - I don’t know whether it is, but it seems too much
RB: Sure
HWM02: They only took me off it, when I went in hospital last time it was 40…
RB: Right
HWM02: So it was so low they took me off the beta-blocker, and the ramipril which they’re not going to put me back on yet. So, really no, I’m okay.
RB: You’re ok, that’s good, that’s good. I want to take you back, if I can [name], to the first time you came in for the [name of other research] study because at that visit, one of the reasons I invited you to take part in this study is because of the conversation we had at that visit when you talked about your diabetes…
HWM02: Yeah
RB: ...and your weight, and you said you were concerned about your weight...
HWM02: I am, always
RB: You’re always concerned about your weight? How have you..how… tell me a little bit about managing your weight - what do you try and do to manage it?

HWM02: I try not to eat *too* much. We always eat a lot of fruit, so that helps a bit but then there's a lot of sugar in some of the fruit, so you can't really gain much that way. The only thing I can do to lose weight is 800 calories a day
RB: Right
HWM02: …and then I start losing weight. But that's extreme.
RB: That is extreme
HWM02: There's a new study, a new thing out now where I think the NHS are paying for it - it's soups and drinks. 800 calories a day. Now if I could get on that, I would lose weight.
RB: Do you want to get on that?
HWM02: How do you get on it? My doctor don't - He wouldn't know about it I don't think, let alone put me on it.
RB: So how did you find out about that?
HWM02: On the news
RB: And your GP hasn't talked to you about it or anything like that?
HWM02: No
RB: Has your GP ever talked to you about your weight?
HWM02: No. Not this one
RB: Not this one. Previous ones?
HWM02: Previous ones yes
RB: And what did they say?
HWM02: "You need to lose weight"
RB: Ok (laughs)
HWM02: Every doctor I see, "You need to lose weight"
RB: And how did you feel about it?
HWM02: It's easier said that done. [Points to RB] You're about 9 stone. Try being twenty stone and then saying it. It's difficult. I'm sure it's, gene-wise, 'cause all my brothers bar one were over weight
RB: Ok
HWM02: My mother was overweight. So..
RB: Do you feel like there's anything in your lifestyle that, looking back if you did it again you could do differently, that would you would change your being overweight
HWM02: I.. I dunno. Because between 18 and 22, I wasn't overweight. I lost it. But I had a hard job then. I was working with my dad on the roof tiling. Everything had to be carried up on your head – all the tiles, everything. And it was hard, up and down the ladder all day, and I lost weight. But if I could change it I would probably stick to a hard job, because that's what made me lose weight. But I was, as a kid I was overweight. We walked.. we lived in [neighbourhood A] and went to school in [neighbourhood B]. We had to walk to the bus, get off the bus in town, walk down to [neighbourhood B] and back… Two miles a day I would say. Had school meals like all the other kids. All the other kids lived just round the corner, not overweight. We walked two miles a day, and we were overweight.
RB: All of you?
HWM02: Yeah.
RB: Except one brother?
HWM02: Yeah. Bar one.
RB: So, do you feel like doing exercise doesn't help you maintain your… well, you must feel it does a bit because although when you were walking 2 miles you were overweight, but when you were doing the hard job then you lost weight.
HWM02: Yeah but it's… I mean to lose a few.. You know, a pound by exercise, that is, it's a *lot* of exercise. That's the way I see it anyway. They had these um, professional rowers and they had a big a meal before they did four-mile row and they hadn't even lost, you know, a pound. Incredible.

RB: You're right, you do have to do a lot of exercise. But have you ever done exercise? Is it something you've ever been interested in.
HWM02: No. I haven't, no. I went to a place in [Town]. We did a bit of exercise. You know after you've had trouble with your heart, you have a session - 12 weeks, 10 weeks I think - which I did. And then there was a lady there done one privately, so I did that. But I couldn't keep up. I was quite ill. I was being sick all the time. Yeah, so I had to give it up. And I used to go swimming, but when I was ill all the time I didn't *want* to go swimming. (Laughs)
RB: And the GPs in the past who told you you should lose weight - did they ever give you any advice on how to do that?
HWM02: Probably give me a leaflet or summat, you know, a diet sheet, but.. Waste of time. Diets do not work or else everyone would be slim and these companies that put them out there wouldn't be rich. That's the way I see it, but…
RB: So when, when you are trying to manage your weight you just cut down on how much you're eating?
HWM02: Yeah, yeah. I mean I lost weight... when I went into hospital first time, I was 134 kilos. When I was weighed here, probably two weeks ago wasn't it? I was 129. And now I'm, according to the scales and thing I'm 131. So I've put on a couple of kilos. So I had lost, you know, 5 kilos since I've come out of hospital, because my appetite wasn't there, not at all. You know I'd only eat half my dinner, I'd only.. Very little. But now, it's back with a vengeance. All the time, I'm thinking oh I could just go and eat something
RB: Hungry all the time?
HWM02: Yeah
RB: And do you still.. The first time you came to see us I remember you saying you snacked quite a lot. Do you still do that?
HWM02: Yeah. Now I do. Where I didn't while my appetite wasn't there. Didn't want it. But now I'm looking, oh I'll have a biscuit. We haven't got cake, pity. (laughs)
RB: Yeah. And do you ever try to change what snacks are available in the house?
HWM02: Not really. We've only ever got biscuits. And they're mainly for our dog. They're you know, rich tea, which she eats, she... She only really has 'em when she goes to bed actually. Strange dog. Put my shoes on today, 'cause we keep her in the cage at night 'cause she's only only small and we don't want to get.. chewing the cables and what have you.. so she goes in there. And this morning I put my shoes on, she went straight back on her bed. She thought we was going out, leaving her
RB: Oh bless her
HWM02: Yeah, she's so nice.
RB: I also remember you telling me one of the first times you came in that when you were keeping yourself busy in the shed you ate less. Is that right?
HWM02: Yeah, because I didn't snack because you wasn't indoors.
RB: So what, what gets you to go in the shed and do your pens?
HWM02: It's just lack of, I don't know, willpower, lack of something, it's just not there at the moment
RB: You're just not feeling it at the moment
HWM02: No. I like doing it when I get in there. It's just a matter of getting up and doing it. I suppose it's being idle isn't it? (laughs) I dunno. I keeps thinking I'll go in there tomorrow, and then something comes up, to go out or whatever. Yeah.
RB: And when you went, 'cause as well as cardiac rehab you went to the Here for Health thing upstairs didn't you?
HWM02: The what?
RB: There's a service upstairs in Blue Outpatients called Here for Health?
HWM02: Oh yeah.
RB: Do you remember going to that? What happened there?

HWM02: Oh they gave me diet sheets. All sorts. Help. It was quite… good, the stuff they gave me but, it was you know, 1500 calories, that's too much - far too much for me.
RB: How much do you think you eat on an average day.
HWM02: Oh about, 2-and-a-half thousand I suppose
RB: Two-and-a-half thousand
HWM02: Yeah
RB: And if you cut that down to one-and-a-half thousand you don't think you'd lose weight?
HWM02: No. I've done it. Many times. The only way I can lose weight is 800, perhaps a thousand. But 800 to a thousand.
RB: Right. And how often have you done that?
HWM02: How often have I done that? 'Bout four or five times
RB: Four or five times, wh.. Over an extended period or just for one day?
HWM02: Yeah
RB: Over an extended period
HWM02: Yeah over..
RB: Tell me how you got into doing that. What made you start doing that and how do you do it?
HWM02: Well because I'd never lost weight doing any other diet, so I thought I'll cut right back. I'll have soup for lunch, just this packet soup with a slice or toast or something – no, I had it with noodles, I put a few noodles in it. And then lunchtime.. Er sorry, I'd only have that at lunch, I didn't have no breakfast, and then at dinner time I would probably just have egg on toast, or scrambled egg on toast, something like that. And that's about it for the day. But you you can't sustain, you can't keep going.
RB: You can't sustain it, no.
HWM02: No. And this diet, this thing with the soups and drinks, that's only 8 weeks I think, then they bring you off it
RB: Right. And how long, when you were doing the 800 calorie thing, how long did you keep it up for?
HWM02: Oh,four or five weeks
RB: Four or five weeks just on 800 calories a day?
HWM02: Yeah. Because I was determined to lose a bit of weight. Which I did. Couldn't say how much now. Definitely lost some.
RB: What made you determined at that point to lose some weight?
HWM02: I was just fed up with being overweight I think. 'Cause it don't.. You know it affects everything, you can't move around properly, can't do your shoes up, put your socks on, that's fucking typical
RB: You'd just had enough of it
HWM02: Yeah, don't you believe these people who tell you that they like being overweight, 'cause they don't. Believe me they don't. No. I mean I was offered a band, not a band, a bypass one. But I was 70 at the time and quite honestly, I thought 70, you know to go through that, at 70… And then you'd have all this skin, you know. It's horrible isn't it? So I thought, no,if you'd asked me when I was 60, 65, I'd have done it. But not 70. But they wouldn't offer it then because I think you had to be a certain weight, you know I think you had to be 50% over your.. you know BMI 50, and mine was 45 I think. They wouldn't do it. But they offered it later on - it changed,
RB: So had you asked for it before?
HWM02: I was offered it when I went to the, I used to go to the place in the [Hospital], the diabetic place, OCDM or something?
RB: Oh I know yeah,
HWM02: And they offered it me there
RB: But you just felt you were…

HWM02: I thought I was too old for it. To be honest. So you see, it's.. 'Cause really I mean they do it laparoscopically don't they, so it's not really invasive, but even so. With my condition, the heart condition it's still a bit dodgy.
RB: So you were worried about, that it would be a dangerous thing to have done?
HWM02: Yeah, dangerous. And I though all that skin hanging all hanging about everywhere, oh my god that's awful. Isn't it? They should offer the skin removal as well. Which they don't. Because they said it's cosmetic.
RB: But that would have bothered you?
HWM02: Oh yeah. If they'd have said oh we're going to do your skin removal as well, like six months down the line, then yeah. I know that's a big operation as well because you've got lots of blood vessels and everything. Yeah.
RB: Interesting. So [pause] I'm trying to think what I was going to ask you now… [pause] I think that's it [name]. Is there anything else you think about your weight? What would you want, do you want, for your weight?
HWM02: I want to lose weight, obviously. But I'd like someone to say, ok we'll put you on this 800 calories a day, and we'll see how you go. If it don't work, it doesn't work. But I know my niece, she was 20 stone, she went on it for eight weeks, she lost helluva lot of weight. But now she's back to where she was. That's the trouble. I think it's all genetics. One day they're going to find a gene and they're going to say "Whoops, sorry!"
RB: I think they have, I think they're aware of it but it doesn't mean you just throw your hands up and say, well that's it, it's too... You know, it's more difficult for some people to manage than others isn't it?
HWM02: I've seen people over my lifetime, they eat god-knows how much, you know they'll have two or three burgers and chips or fries and they never put on a pound. One of my sons is like that. The other one has to watch everything he eats. And my daughter. They, they're.. My daughter, she's a clone of me actually and she has to watch *everything* she eats or else she just pyu.. [makes expanding hand motion]. She's not too bad at the moment, she's about 12 stone I think, so it's not too bad. But yeah, she has to watch her weight. And her last daughter who's with her second husband, is going the same way, you can see. She's eleven but she's, she's on the tubby side. She's not fat, but if they don't watch it she's gonna go that way. But the other three kids, with her first husband, they're like rakes. They are! And they eat god-knows how much, they can eat anything, they eat all the rubbish under the sun. Never put on a pound. But then their father was like that, he was thin, very thin. So again, genetics.
RB: Genetics, yeah
HWM02: Like this Lynch syndrome that [wife]'s got, it's affected one of my sons, the other one won't be tested, but my daughter luckily enough hasn't got it. So it's genetics, it's all genetics. That's all it is.
RB: What does [wife] think about you losing weight? When you're trying to lose weight, what does [wife] think about it?
HWM02: She likes it, she says yeah, you know, do what you can. So she's for it. But sometimes she says oh you don't wanna do that at your age (both laugh). She's probably right.
RB: What does she mean by that? Ok the bypass was one thing but does she mean exercise or not eating something, what's she talking about?
HWM02: No she says, you don't want to start trying to lose weight at your age. 'Cause when I said the other day, Christ my appetite's gone wild, she said well good. I said well why is it good? She said well last time you couldn't eat anything, now you're...
RB: (laughs) She's looking after you then?
HWM02: Yeah, trying.
RB: Yeah. How's she getting on, is she alright?
HWM02: Yeah she had another bout in the bladder which they took out. Then she's going for a colonoscopy next month. But, it's only six months, they said to her every three because they

grow very quick in the bladder. But apart from that these Vitamin B12 jabs she has every 12 weeks. They might as well, oh the last three weeks before it she ‘s just a different person.
RB: Is she?
HWM02 Oh, terrible. She can’t do.. She’s weak, got no coordination , her mind’s not always where it should be, oh terrible. But they won’t do it every ten weeks. They will not do it. If it was because it’s an extra one during the year well, ok, we’ll pay for it if necessary, but they won’t do it
RB: I wonder why...
HWM02: I don’t know. She’s asked them time and time again. Because, well I just wish someone would, could see her when she’s like it because she’s a very fit woman - she does all the gardening, she does all the housework, she’s always busy, always doing something. But when she’s, the last three or four weeks before this is due which is now, she’s a very very different woman. Different completely. Gets very tired. Well she’s 73 but that’s… not the point, she’s normally so active. But there you go , that’s life, they won’t do it, we tried. They do, there’s a girl down the road they do it every 8 weeks but she’s got some underlying problems as well. So… I don’t know if it’s a question of money - it might be a question of what the licence says for the injection I suppose
RB: It might be something like that. But they should tell her that [name]
HWM02: Yeah, they should. No-one ever explains.
RB: Then you’d know, wouldn’t you.
HWM02: Yeah. I might write to ‘em. Ask them what’s going on.
RB: That’s a good idea.
HWM02: Yes. Are we done?
RB: We’re done if you want. I’ve just got one more thing to ask you - I’ll just turn the recording off [to speak about the other research study]. Thank you ever so much for doing this.

[END]