HWM11 22-Jan-2021 Interview transcript (participant was in car, with wife, having had to go into work after breaking laptop at home. I offered to postpone interview but participant preferred to go ahead)

RB: So what I normally do to start with is go through a couple of questionnaires with you if that's alright, about your symptoms

HWM11: Yes

RB: Your AF symptoms. Er, so the first..

HWM11: No problem

RB: ..first question is your gender

HWM11: Male

RB: And the second is your year of birth

HWM11: 1962

RB: 1962, great. And are you in atrial fibrillation currently?

HWM11: Yes, I am, yes.

RB: Yes, so you came in for an ablation didn't you?

HWM11: I did yes. Following that I ended up back in it. As far as I'm a.. as far as I'm aware, I sent the traces from - I'm on a Kardia machine as part of the study [participant is referring to CAPLA study] and I sent, I sent traces to the arrhythmia nurse, and she told me that I'm in AF, and each of the traces it now comes up with "Possible atrial fibrillation" on the, on the y'know..

RB: Sure, sure. And are you feeling i.. are you feeling your symptoms of AF, can you feel that you're in AF?

HWM11: Um, I.. it's not as bad as it was initially. Initially I was, I got up to 163 beats a minute and I, I could feel that when I laid in bed banging about so it's not, it doesn't, I can't feel that as much but I do get short of breath, um, and having that mask on whilst talking to the boss a minute ago made me short of breath

RB: Yeah, yeah. And trying to explain to him how you'd broken your laptop no doubt as well.

HWM11: I was trying to, yeah, trying to explain and then she told me that the bloke who does it is actually in hospital so he's going to be off for 6 weeks

RB: Oh no!

HWM11: .. So I've kind of killed it and she gave me the number of someone who said they could try and fix things remotely, so that's not.. that ain't gonna work. But luckily I have got another one it just means I have to wear headphones, but never mind. It's me own fault, it's me own fault [both laugh]

RB: Oh well. Next question is…

HWM11: She was less than impressed

RB: I bet! Next question is “How do you feel about your life at the present time?”. If 1 was the worst possible life and 10 was the best possible life, where would you put yourself?

HWM11: ‘Bout 5

RB: About 5, okay. What’s making it a 5, why do you say a 5?

HWM11: Just the.. the restriction, yeah just the restriction and er in terms of er not being able to do.. you know I’m just getting fatter and fatter because I can’t walk very far, I can’t do anything, I’m someone who likes to do stuff, um and I’ve had issues with mobility because I’ve had my foot reconstructed, um, and I was hoping to get that other foot done and there would’ve been an end to it all, but now my heart’s gone wrong again it’s kind of prolonged the whole process so it.. it’s, unfortunately it makes you.. you know just.. it, it limits what you can do physically.

RB: Sure. So what’s causing you the most limitation at the moment, is it your heart?

HWM11: Yes, it is at the moment. I was, I was doing quite a.. you know ‘cause I’m a teacher so.. and I teach a practical subject so I do a lot of moving around within the day you know within my workshop and school, um, and that was creating a fair amount of pain in, in one of the joints on my foot that I had reconstructed and so that was actually quite painful. But since I’ve been off for an extended period due to the online tuition and stuff [because of COVID lockdowns] that is no longer hurting so I think perhaps its had a chance to repair slightly – ‘cause that was the bit that went wrong before but I think the er, you know the, the heart is er, is very limited in terms of what I can do

RB: Sure. And what would you like to be doing, if you weren’t being limited by your heart?

HWM11: Well, I, you know, wanna get me weight down, do a bit of exercise. Once, once I’ve had the other foot done I shall be able to walk around a lot more. I mean I can walk around now, it’s just things, even little things like washing the car, this was something that before when I was admitted to hospital - this is before the ablation – and in fact what was the cause of the referral that led to the ablation was the fact that I was washing me car and uh, you know I’d ended up in AF again, my heart had already gone, but it was, it was getting progressively worse and it got so that I literally couldn’t take a few steps into the house without having to stop and catch up on me breathing, it, you know.. They put me on digoxin which seemed to calm it all down, calm my heart down. It seems that when my heart races and speeds up that’s when I get the severe symptoms.

RB: Yeah

HWM11: I’ve now, I’ve had the digoxin reintroduced following the ablation, ‘cause my heart rate went ridiculous. And they’ve doubled the dose now so I’m actually on twice as much digoxin as before I had the ablation. And that has calmed it because it’s dropping gradually. I’m still at 122 today, beats a minute, and I do get the breathlessness, yeah. As you, as you probably noticed when I had a mask on and I literally just got out the car, walked not.. hardly a few yards into work and then walked back again and that was enough to you know, leave me short of breath.

RB: Yeah, yeah, ok.

HWM11: You know I understand there's supposed to be a three month time when it, it should settle down but um so far the indications are that I'm straight back in it

RB: Yeah, it's not settling down

HWM11: So I hope, I'm hoping that it does better, that I don't have problems…

RB: Yeah, and are you continuously in AF at the moment?

HWM11: Yes. Yes. Every, every trace. When I was in the hospital they gave me this machine that.. admitted it only works on two fingers doesn't it – I think you gave me it! What am I on about?!

RB: Yeah that's right the Kardia device

HWM11: What am I on about? You gave me it! [both laugh] I've been doing that morning and night. Apart from two that were done on the ward before I went home..

RB: Yeah, 'cause when I did it with you it was in sinus wasn't it?

HWM11: Yeah, it, it said normal didn't it? It did two normal ones, the next day it said unclassified – I think I had two, two or three unclassified ones, when it was thinking could be a bit dodgy, and then after that every single one has said possible atrial fibrillation

RB: Sure, ok

HWM11: Whether that's due to the fast heart rate I don't know but when I, I sent those in to the arrhythmia nurse and she said it was in AF. Um hence the shocking appointment – I'm going in on [date] to be shocked

RB: Oh are you? I might see you

HWM11: Oh sorry I should have mentioned that probably straight away!

RB: No that's alright

HWM11: They sent me an appointment, they sent me an appointment today on email. Tomorrow I've got to go for a COVID test at the Churchill Hospital. And then on [date, time] I've got to come in to have another cardioversion

RB: Cardioversion, sure

HWM11: I think that'll be my third or fourth one. I'll be doing them meself soon!

RB: Yeah! If I asked you to rate how severe your symptoms are from 1 being not at all severe to 10 being extremely severe, how severe would you say they are?

HWM11: Well that's difficult, that's difficult really because mine occurs on exertion. So you know I mean if I'm sitting there at rest my, my symptoms are you know ok I can probably feel my heart beating if I put my hand on it, likely I'll be able to feel it like out of rhythm, but I wouldn't, I wouldn't say I have massive symptoms unless I try to do something. And it, you know, that is the limiting factor really.

RB: Yeah. So now you're sitting in your car at rest, if I asked you to give me from 1 to 10 where would you say?

HWM11: Well I'd say about 5

RB: 5. And when you're walking about what would you say it is?

HWM11: I'd say it was about a 9

RB: About 9. Ok. Now the very first time…

HWM11: Particularly if I was walking – sorry- particularly if I was walking up the stairs

RB: Ok, that's really bad then, yeah?

HWM11: Yeah, if I'm walking up stairs it does have an effect on my breathing

RB: Yeah, yeah. Can you tell me about..

HWM11: It's my heart didn't..

RB: Sorry go on

HWM11: I was just saying my heart didn't tolerate being out of rhythm and beating fast. That's how I ended up with a blood clot on my lung before. If you see what I mean

RB: Yeah. So the very first time you had AF, can you tell me what happened? How did you come to be diagnosed?

HWM11: How did I.. what originally?

RB: Yeah

HWM11: Er yeah, we were on a family trip down to the south coast and… um.. it, I had, I had problems with breathing and I had pain in my chest which got progressively worse during the break as we were down there. And when we returned from there, can't remember w.. did I go to the doctors? [wife affirms yes] I went to the doctors' surgery. One of the doctors there, he wasn't my regular doctor, um he examined me and told me that it was ok, um and sent me off again. Um and I then had to go back down there after a few days I think because I think we phoned up and complained that the symptoms were getting worse. And I saw the head doctor, the partner, Dr [name], and she assessed me and sent me directly to the hospital after doing an ECG, sent me directly to the hospital to the ambulatory part of it, so you walk in, where they managed to leave me sitting for 10 hours in a chair which was really boring. And then I was admitted onto the cardio ward in [hospital name], where they, they did tests on me and discovered I'd got a blood clot on me lung and a fast heart rate and AF. So that's when, when they.. they were giving me injections into my stomach then of the blood thinner. I had numerous scans and heart scans because they wanted to see if there was any damage. I think what they found in the end was that although the.. although it had gone wrong and it was beating fast and there was a blood clot and everything, there was no lasting damage to the heart, or you know, only minor, only minor things . They used a lot of technical words but I think it meant that there was no permanent damage. That helped!

RB: And how long ago was this?

HWM11: About three years ago now

RB: Three years ago. And if I again asked you to rate from 1 to 10 how severe it was right at the beginning, how severe would you say it started off as?

HWM11: Oh I'd, I'd say about.. well, by the time I'd finished, you know, I'd gone into the surgery it was about a ten – I could barely walk a few steps without gasping for breath so it was pretty dangerous I think.

RB: Yeah, ok. And then you've been cardioverted you think 3 or 4 times?

HWM11: Yeah, I'm losing count! I thought it was… [wife speaks inaudibly in background] Yeah it depends if you count more than one attempt in the same version. If you're counting ones in the hospital for it, I think they did it twice during the first one, and then I was definitely done again, I was done again in Northampton and they told me it had worked and by the time I was sitting in the bed on the ward, within about half an hour it had jumped back out again

RB: Right

HWM11: That was in October this year. Or last year should I say

RB: And then you had the ablation, and then you're coming in on [day] for presumably your third ablation er your third cardioversion then

HWM11: Yes, yes. I'm like your best customer really, to be honest!

RB: Yeah! You don't get Nectar points, I'm sorry.

HWM11: No! Nevermind, nevermind.

RB: And in the last year have you had to go into the Emergency Department at all with your AF?

HWM11: I've been once, yes, that was when, when I was working me car and that and it progressively got worse before then. Um, and you know then we found it had jumped out. And they took me in, I had to go into A&E where I was assessed and they admitted me to the cardio ward in [hospital] overnight for assessment. And then I was sent home with digoxin which I wasn't on before and a GTN spray. I thin initially in A&E they gave me the GTN spray thing which gave me a bit of relief because I wasn't feeling very well at all. So that helped a lot then, but I haven't need to use that since whilst on digoxin. And I stopped the digoxin and that after the cardioversion – sorry, the ablation, getting cardios mixed up now [laughs] – yeah after the ablation sorry they stopped the digoxin then because they said there wouldn't be any need for it. And clearly the rhythm has changed it has created the problem again and their advice when I contacted them again was to resume digoxin. They asked the consultant, Dr [name], or Mr [name], whichever you call him

RB: Doctor

HWM11: Yeah, that's it. And he suggested starting the digoxin again and then they decided to double it, um, 'cause it wasn't having hardly any effect initially. So once I started taking two of the tablets instead of one, now it appears to be coming down.

RB: That's good

HWM11: So we're going sub-one hundred occasionally

RB: Oh! Getting there!

HWM11: It's been 98 occasionally, so we are, we are getting there. You know, it has felt better since being lower, I have to say.

RB: Yeah, it must do

HWM11: But I still appear to be getting out of breath so you know, it hasn't completely stopped the symptoms

RB: Yeah, ok. So over the past year how many times have you had to see a doctor for your heart?

HWM11: Only, only the once. When I was, when I had to go in and be admitted in October yeah. Yeah, because largely, once the problem was noted, it's been kept under control with digoxin. Although it doesn't stop all the symptoms, it does seem to stop the you know, feeling of unwell. And I was on blood thinners already, so that's been good. It's not so good if you do a job like mine where you're constantly cutting yourself all the time

RB: Yeah, power tools and blood thinners don't go great together do they? Or hand tools..

HWM11: Yeah, oh my god, I'm constantly putting blood on somebody's wood! [laughs] Never mind. Yeah, it's one thing after another isn't it? Yeah, so that.. yeah. So once I would say.

RB: Ok sure. I'm going to go through different kinds of symptoms now and how often they bother you. Because you… different people get different symptoms with AF. So palpitations, which is thumping in your chest, has that bothered you at all in the past four weeks?

HWM11: I would say it has done at night, yes, when my heart as racing really badly due to the AF after the ablation. It was, it was actually uncomfortable because you know when I lay on me side, on that side, I could feel it and I was finding that I needed to lay on me back, like, it was literally thumping on the bed and it, it wasn't very nice and I could feel it, I could feel it in myself like a tremble. Not a tremble of the hands but I could feel it was kind of like rocking your body slightly if you know what I mean – you could feel it throughout your body it was going that mad.

RB: Sure, so if I asked you to say a little – sorry – very little, a little, a fair amount, a lot, or a great deal where would you.. how much would you say?

HWM11: I'd say a great deal.

RB: A great deal, sure. Now, shortness of breath at rest - it doesn't sound like that particularly bothers you

HWM11: Um, occasionally. When I'm sitting down, you know, particularly at night if I'm watching the telly, there are occasions where I just.. you know it might come over me occasionally where I'll just.. I have to deep breath a bit for a while. I know it sounds odd but you know occasionally it does that and I've done that quite a few times so I wouldn't say it doesn't affect me

RB: Ok, it doesn't sound odd, lots of people have that problem. So would you say very little, a little, a fair amount, a lot or a great deal?

HWM11: I'd say a fair amount because it does happen fairly regularly. Um it it's just kind of like random – all of a sudden you, you need to take a deep breath and sort of, y'know, several more. It's weird. I guess that's because it's not getting enough oxygen, perhaps

RB: Yeah, yeah, ok. And then shortness of breath during physical activity, would you say a great deal/ Or a lot?

HWM11: I'd say the maximum one

RB: The maximum, yeah. So the next one is tiredness or fatigue at rest – do you get that at all? Do you feel tired when you're just sitting?

HWM11: I haven't had a great deal of tiredness although I do tend to fall asleep so perhaps I'm more tired than I think I am. I occasionally fall asleep at night in my chair and, and when you consider how much exertion I'm actually doing – which is virtually zero at the moment because I'm not at work, I'm teaching on line and that, all that involves is going upstairs and sitting on my bum all day – it's um perhaps, perhaps I'm suffering more fatigue than I would do normally. I guess if I was at work and I was working everyday, you know, in a physical way, I guess I would be, yeah..

RB: It might be understandable

HWM11: ..because of the circumstances of the COVID thing at the moment, I'm not really suffering those you know those problems.

RB: Yeah. So would you say very little, a little, a fair amount, a lot or a great deal?

HWM11: Um [pause] I'd say.. a little

RB: A little, sure. And what about during mild physical activity, do you get fatigue then?

HWM11: Yeah I, I think you could say that I was disproportionately affected by the fatigue for what I've done. So I would do a little amount and I would've had enough, if you know what I mean, whereas normally I would carry on

RB: Sure. So would you say it bothers you a fair amount, a lot, a great deal?

HWM11: I'd say a lot

RB: A lot, sure. Do you ever get light-headed or dizzy?

HWM11: Um, there was a period of time when I was getting dizzy, yeah. Getting, I was getting lightheaded and feeling a bit dizzy but it seemed to sort of dissipate as time went on. But I can't

remember abouts when that was, but I think it was prior to going in and getting the digoxin I think it was making me dizzy as well?

RB: So have you had it in the past four weeks?

HWM11: No.

RB: No. Okay. And what about that chest pain – have you had that in the past 4 weeks?

HWM11: No I've not had the chest pain since the first…

RB: Since the first time

HWM11: Since.. since the first time that I had it, due to the medication I guess

RB: Ok. I'm going to go on to the next questionnaire now which is about your quality of life. And they're very simple questions, they're about your quality of life. So the first one is..

HWM11: Ok

RB: ..about mobility and the options are I have no problems in walking about, I have slight problems in walking about, I have moderate problems in walking about, I have severe problems in walking about, or I am unable to walk about

HWM11: I would say I have, yeah, severe, because over distance it does make me breathless

RB: Severe sure. Yeah. Next question is about self-care, so washing and dressing. Do you have no problems, slight problems, moderate problems, severe problems, or unable?

HWM11: No

RB: No problems?

HWM11: No problems.

RB: Sure. Then your usual activities so work, study, housework, family and leisure activities - no problems, slight problems,, moderate problems, severe problems, or unable?

HWM11: Well I'd say moderate problems because you know, I'm not, not that I do a lot of house jobs but I am head of bin emptying and hoovering, which I do like doing. But that involves, that does involve carrying the hoover upstairs and around about so I would say that gives me quite a lot of problems, just with weight, 'cause I've got Henry and Henry's got a fair old load on – not that that would have bothered me even in the slightest previously, but you know it would leave me short of breath. If I was carrying Henry up the stairs, which I didn't do but I carried an alternative Hoover up the stairs today, you know that leaves me breathless when I get to the top of the stairs. It's like walking upstairs twice if you like, at the same time. So yeah I'd say I have problems with that.

RB: Um, now the next question's about pain and discomfort and this would include things like your foot as well so not just your heart. Do you have no pain, slight pain, moderate pain, severe pain, or extreme pain?

HWM11: I would, I would say at the moment in terms of pain 'cause I'm not.. 'cause I'm not at work and I'm not, I'm not moving about like I would plus the heart is limiting my movement so I'd say I was in.. I have moderate pain I would say. But you know when I, when I, when I was at work before all this happened, and not just at work but COVID as well, you know I've ended up with a permanent limp because the pain across the top of my toes is so bad. I'm gonna take meself back under warranty, unfortunately. But I want to have the other side done before I complain about it, otherwise I'm gonna end up with uneven feet

RB: Yeah you need to get 'em both done don't you. The next question's about anxiety and depression – do you have any anxiety or depression?

HWM11: Not really no

RB: No. And then the last question is about your health in general, so if nought was the worst health you can imagine and one hundred was the best health you can imagine, where would you put yourself on that scale?

HWM11: Well I think, I think I feel like I'm at least 70

RB: 70. Ok, that's good.. and what would you..

HWM11: Well it's just

RB: What would your priorities for improving your health be, what would you like to improve the most about your health?

HWM11: Well, I'd like to improve.. what do I want to improve about my health? I want to improve the other foot really to make it more [wife speaks inaudibly in background] yeah you know to make it easier to walk around. 'Cause with the other one it's turned over a bit and I end up walking on.. if I walk on gravel I end up with stones in the side of my foot, it's really not good. And you know that's what's causing me problems. And then, you know, I intend to lose a bit of weight. But it is, it is a bit difficult because I've got a replacement knee as well, it's all a bit clunky now, but you know I do intend to lose weight and er hopefully make meself a bit more healthier. Or lighter.

RB: Yeah, ok. Gonna talk a little bit now about ways you manage your weight, because obviously it's very difficult to exercise um, at present. Have you always been big, or have you put on weight as you've got older?

HWM11: I've put on weight as I've got older.

RB: Sure. And what do you think is causing you to put on weight most of all?

HWM11: I've I've put on a fair amount of weight when I was, when I was so.. I was off for three and a half months with my knee, and there's not a great deal to do. There's not a great deal to do when you're off apart from watch telly and I guess I ate more stuff than I should have done. And then similarly I was off for three and a half months yet again when I had my foot done. So I've spent, I spent – what with the heart as well – I've spent the majority of virtually a year off with little to do and little chance of mobility so anything I ate, I wasn't able to burn off at all. I think I've mostly put more weight on then. I've definitely put more weight on recently than I had before. And I did lose.. I

lost over a stone last summer but then.. ‘cause I, you know due to everything that’s happened I guess I just ate and it’s, it’s just piled on. Plus I’m getting quite old and you don’t burn it off as much do you

RB: No, that’s true

HWM11: So yeah, I know, I know what I’ve got to do to try and improve. I have got a bike but um, I was planning to get on that but I’ve not managed that yet – couldn’t I don’t think at the moment, probably kill me [laughs]

RB: So your plan for losing weight would be, would be mainly to increase your exercise?

HWM11: Well yeah and not eat so much

RB: Sure. So um tell me about your diet – what sort of things do you eat and how would you change that to lose weight?

HWM11: Only the healthiest… I don’t like salads and I don’t like vegetables which is - and fruit – which is probably the biggest reason that I’m fat..

RB: You sound like my husband!

HWM11: ..but um, yeah?! But I don’t though, I never have. It’s never been a massive problem and I think it’s because, because now I’m old and my metabolism doesn’t work much so you can’t eat the same stuff and then expect to, to not put weight on. But you know, there are things I don’t need to eat. There was a time I lost, was a long time ago now, but I lost four and a half stone. And um, I didn’t have anything from McDonalds and stuff like that, you know, sometimes it’s the convenience isn’t it? And we’ve got one just down the road. Um you know, so I need to avoid McDonalds, avoid all the things that I did before, and er the weight does tend to drop off once I do that.

RB: Mhmm. So what gets you motivated to do that?

HWM11: Um.. well I think once you start it and you see the weight coming off, it’s sort of self-motivation then. Er, it has a sort of, it has a motivation effect to see yourself getting slightly lighter. And the last time we did it, you know, we.. we.. we were both doing it, meself and the wife, we got some of that Slimfast stuff and that was working quite well.

RB: Oh ok

HWM11: But I think you get to.. you get to a point where you’ve got.. I think for us it might have been the time when our daughters all had birthdays and stuff and then there was lots of meal out and things and you know it, it, it just sort of petered out whereas you know if we, when we start doing it we should be alright. And stick to it. So it is do, it’s doable.

RB: Yeah

HWM11: I don’t have to sit there with a mountain of doughnuts or anything

RB: It’s interesting what you said about your daughters’ birthdays and having lots of meals out ‘cause this is something I hear quite often doing this study is people have started to lose weight and

then it's been Christmas, or there's been a holiday or a wedding or something's happened that's meant they've had a few meals out and then it's kind of been the start of them putting back on weight. Your daughters are going to have birthdays again next year, so when you get to that point, say you are losing weight and you get to that point what are you.. are you just going to stop again or have you got a plan in place to…

HWM11: Well there's another, there's another reason next year why you know why I need to lose weight, 'cause my daughter's getting married

RB: Oh! Congratulations!

HWM11: So yeah thank you. So that I don't look like, um, like a horse in a jacket I've got to lose, lose weight to buy a new suit so you know I will be, I will be losing weight probably this year going into next year as well so that, yeah, so that I don't look so fat on the pictures basically

RB: Sure, so have a got a target?

HWM11: Er not at the moment [laughs]. My target is to get my heart working first

RB: Right, get your heart working and then get your weight sorted out

HWM11: Yeah, um.. I think also the more the more busy you are, the less you're going to want to eat all the time, if you know what I mean. I mean I've off work on and off for ages, but when I am at work they load you up with so much stuff that you tend to be busy all the time, which gives you less time to er, to worry about eating. Hopefully.

RB: Yeah, yeah. Have any doctors or other health professionals ever talked to you about your weight?

HWM11: No.

RB: You've never had anything when you've gone in for your foot, or your knee or you've been to see your GP, nobody's ever mentioned your weight?

HWM11: I think, I think the man.. well the man with the knee, he said um, you want to try and lose weight as it will help the knee, won't wear out so quick. That was all he said

RB: Sure. And did that inspire you to lose weight, or did you just think, oh yeah, next year?

HWM11: Well you know I'm always thinking well I know I need to lose weight and I have started to do this a couple of times and for a long time.. The last time, when I lost a stone and a bit, that, I kept that off for quite a while, and even when, when I thought that I was eating more than I, you know, started eating more than I had been, it was I'd not.. I know, I know that I was still thinner. I think I went er, I needed a smaller trousers again so that was an indication that I've lost a bit of weight. Yeah. Yeah. I've forgot what I was saying now, but yeah.

RB: That's alright. But no.. when you've been to see cardiologists, um, or when you came in for your ablation nobody talked to you about losing a bit of weight?

HWM11: No, not for the ablation. I do believe that the consultant on the heart thing, Dr [name], I think she might have commented on weight. She did I think.

RB: Ok. Can you remember anything that she said?

HWM11: Well I can't remember exactly what she said but I think it was around the weight issue. But none of them, none of them have said that the weight was an issue for any of the procedures that were going to be done, so I didn't make much of it other than to say you know that.. But it's usually that if you lose a bit of weight then.. I don't know I can't remember what they said but basically lose some weight – it wasn't an order, it was just advice. But then I probably wasn't quite as fat. But then I think on the last few times that I've been weight in the hospital situation, on the cardio front, the nurses have said oh the BMI is well within, you know, your height and age and everything for this operation.

RB: Right ok. They haven't said you're an absolute wreck and there's no way that we can work on you. [laughs]

HWM11: Well they haven't shouted "Get the forklift!" [both laugh]

RB: So the reason I'm doing this study is.. since 2012 some research studies have been coming out that have shown that if people are overweight and have atrial fibrillation and lose weight, they can really dramatically improve their symptoms and improve the functioning of their heart. Um..

HWM11: Well yeah I'm up for that!

RB: Aha, but nobody's actually talked to you about that when you've been in with your atrial fibrillation?

HWM11: No, no-one's sort of linked it to that. They've just sort of said that it would be a good idea. Mostly the knee person.

RB: Yeah, ok.

HWM11: And he was just thinking of the joint loading

RB: That's logical isn't it?

HWM11: [pause] It is. It is.

RB: So when doctors and nu.. other health care professionals talk to you about your weight, how does it make you feel?

HWM11: Er, well luckily they've not been too scathing so it's not really worried me too much.

RB: Sure, you feel like it's been quite positive..

HWM11: But I do know, I do know that I.. you know I would like to lose some weight because er you do feel better when you've done it. Especially if you need to go and buy thinner T-shirts – I mean I've got a load that I was in and then I ne.. I could do with getting back into them. So yeah. Yeah. It does make you feel good, it does make you feel good if you've achieved it. It is an achievement I guess.

RB: Yeah, absolutely, absolutely. Is there anything that you would like from the NHS to help you lose weight? Are there any services that you think it would be beneficial for us to provide?

HWM11: No I don't think so really. Unless there was a Slimfast Department.

RB: Sure well yeah I mean if there was, if they said to you oh we can refer you to this department that can put you on a.. a meal replacement diet for example, is that something that you'd be interested in?

HWM11 Yeah, as long as it didn't contain too much in the way of fruit or vegetables I'd be fine!

RB: [laughing] So it would have to be tailored to your preferences!

HWM11: Yeah!

RB: So I'm talking…

HWM11: Yeah, I mean I think the shakes we were having were like chocolate or strawberry. We had the Slimfast shakes. And it, you know, it was doing.. there was bars as well that we were having, meal replacement bars we were having those. You know and it wasn't unpleasant and it was you know.. The worst thing about it was taking the time to eat it, 'cause it was a bit y'know, a bit tough going. But y'know once you'd done it that it.. yeah, it was fine

RB: What do you mean it was tough going, was it not.. [pause]

HWM11: They were, they were, they were sort of.. I don't know what they were made out of but they were.. once you started munching on them they weren't a five second job. They looked like you could wolf them down but they were, y'know, took a while

RB: Oh I see! The bars, not the milkshakes

HWM11: No no no the milkshakes didn't take that long. We bought a machine as well to mix it up

RB: Aha.

HWM11: So y'know. The only thing that puts you off doing that is the cost of it all, 'cause it is actually really expensive. And it doesn't last very long y'know, you buy like a fair amount of it and they don't last very long once you start doing them every day.

RB: No that's true that's true

HWM11: If you see what I mean. But yeah.

RB: But that sounds like it worked well for you

HWM11: Yeah it was working, it was working quite well.

RB: Ok. Sure. And if um you went to an appointment at the hospital and they said oh we're going to refer you to a department to help you lose weight, how would that make you feel? Would that be something you'd be interested in or something you prefer to be left to your own devices with?

HWM11: Yeah as long as they didn't want to lecture me on fruit and vegetables 'cause I still wouldn't eat it, it's horrible you know and I never have, um, that's the only problem. As long as it, as long as it wasn't like a lecture in nutrition, as long as it was like "well what do you, what do you like" – I don't mind having anything as long as it's like, like… I dunno, like stuff that I normally eat. And not the fats.

RB: Yeah, if it was something like "We need you to switch to this type of food instead of type of food", just like lower fat food rather than higher fat food or keep a food diary for example um

HWM11: Yeah we do that, we kind of do that anyway in terms of low fat things. You know we have quite a few things that are the low fat option.

RB: Yeah. What about the McDonalds, is that.. you know talked about the convenience..

HWM11: I only have the low fat option [laughs].

RB: How often do you have a McDonalds?

HWM11: Unfortunat.. Yeah thing is.. I don't have to go to McDonalds it's just [wife speaks inaudibly in background] Yeah my grandson he loves to have McDonalds on a Saturday so I end up going with him for a McDonalds breakfast and then he has a .. he stays the weekend and we, I suppose we spoil him because he's.. y'know he onl.. he comes and stays two days a week and he loves KFC so we have a KFC so to make it easier and while I'm there I usually get a burger and a chips from McDonalds on the way up on a Saturday. It's just easier, y'know it's just easier while I'm there, and I think oh I quite fancy that. But I don't have tons of stuff, I know that some people have loads and loads of stuff, but you know, I might have a chips from McDonalds and then I have the drink from his meal 'cause he doesn't want it. But I shouldn't really drink that 'cause it's diet coke and I know that's very naughty with the heart

RB: So if you were to go on.. say if you get your heart back in rhythm soon and you go on this.. go on a bit of a health kick, and your grandson wants to go to McDonalds on the Saturday morning, how's that gonna be for you?

HWM11: That's fine I'll take him and I just won't have anything, I'll just wait until I get home. I was doing that before, when we were doing the shake things. Yknow, I was, I was having a breakfast bar I think they call 'em when I got back. So y'know, I could do that again.

RB: Out of interest, I mean the shakes and so on, they're nothing to do with your heart, you could do those without being in.. while you're still in atrial fibrillation, what's holding you back at the moment?

HWM11: Um.. well I suppose nothing really, but er I suppose it's just a feeling of wanting to be, wanting to have your heart in the normal rhythm, y'know, just makes you feel better doesn't it. So it might be nicer when I haven't got anything going on.

RB: Ok. Yeah

HWM11: So I don't think I've had, I haven't had any time for the last couple of years when I haven't had anything, or three years, when I haven't had anything sort of going on. It'd just be nice to be.. you know have it all finished but I know that's not easy. The way it's going.

RB: No I understand. It's quite an interesting thing..

HWM11: You know.

RB: Um..

HWM11: But if, if losing a lot of weight is the key to keeping my heart in the right rhythm, then I'll do it.

RB: Yeah yeah. I ju.. I always find it quite interesting because a lot of people have said a similar thing to you – "I want my heart to be sorted, and then I'll lose weight", um or "I want my knee to be sorted and then I'll lose weight" – um and it's a kind of cycle, and I wonder at what point people say "Oh if I lose weight, then my knee will be better" and sort of turn it around? Does that make sense?

HWM11: Yeah, I understand that. I mean I've been lucky that my knee has been I guess a perfect fit so far, in as much as I don't get any pain from it now and it's not troubling me. I mean I guess if I had a lot of pain from it even after the joint then I would, I would probably think oh I need to make sure I lose a load of weight. But um yeah. I do understand that they wear out quicker if you are heavier. So um, yeah. I shall be losing weight [pause] But I blame my daughter 'cause she bought me a voucher for two Indians

RB: Oh ok – her fault! [laughs]

HWM11: Yeah, seeing as you have to eat that up really

RB: Well you don't want it to go to waste do you?

HWM11: Well I don't want to insult her, you know

RB: Alright I think that…

HWM11: Having said that I have used it [laughs]

RB: I think that's all the questions that I had Alfie, and did you have anything else that you wanted to talk about with regards to your heart or your weight management, or anything that you would want from the NHS?

HWM11: No not really. Um y'know I, I will be losing weight and I, y'know.. Well, one of the questions would be is there any mechanism with the hospital that monitors your weight ongoing, or some.. I think they kind of.. they finish their involvement with you if you don't have any further problems

RB: Sure is that something that you would want?

HWM11: Well I was just, I was just thinking you know if.. do.. y'know I don't know is there any value for the hospital to be monitoring your weight, so that obviously it could have an impact on the – not just for me – but for the NHS bill globally. I don't know, if they were to monitor people's weight and

suggest.. or if there's conclusive proof that losing a bit of weight would make a difference to this heart rhythm, I don't know what you're trying to prove anyway

RB: Well it's not what I'm trying to prove, so there's a couple of other studies that are going on at the moment that are still continuing to investigate this, um, but it does seem that there is a mechanism for weight loss to improve atrial fibrillation. Um, and also not only atrial fibrillation but other illnesses like diabetes can be reversed in some people by losing weight. So there is a phenomenal opportunity for the NHS to save money in the long term by helping people to lose weight. But the communication of this – I'm finding – the communication of this to patients has been very slow. And of all the people that I've talked to for this study, only one person has been sat down by their cardiologist and talked to about this. And interestingly it was Dr [name] your same cardiologist who mentioned it to you as well, um, but not quite perhaps in so much detail.

HWM11: Yeah, yeah, I think there was a .. she is a nice lady actually. And there was a, there was a person, a consultant on the wards in [hospital name] I don't know who she was, she was a bit abrupt, and um she was the one.. talking about heart and rhythms and things and I said well you know I am drinking diet coke instead of.. and she said "Diet Coke!?" and she ripped me off a strip [both laugh] so I went onto ginger beer after that. So there you go, there's a lifestyle change!

RB You swapped from diet Coke to ginger beer!

HWM11: I did. Yeah.

RB: Do you drink a lot of ginger beer and diet Coke and stuff?

HWM11: [Wife says "You don't drink tea and coffee"] I don't drink tea and coffee, um, I've never liked those, I like a cold drink so I do um I don't drink as much diet Coke now as I did, 'cause I used to have that regularly, but I tried to cut that out in favour of ginger beer, which didn't seem to have caffeine in it

RB: Sure. And how much ginger beer would you drink in a day?

HWM11: Um oh, couple of glasses at night. I don't drink it during, I don't drink it during the day

RB: It's not the only thing you drink?

HWM11: [pause] Uh no, I can drink water and.. you know I'm a pretty versatile water drinker

RB: Ok

HWM11: And well you know I can drink other cold drinks [laughs] so yeah I suppose I don't drink that much. I don't drink alcohol now in any form ever. Um yeah. Since I've had so many tablets.

RB: Yeah, ok. But yeah going back to the NHS services, you think a sort of weight monitoring service and I mean.. what would you, how do you want that to work? Do you want them to phone you up and say, ok you're tipping the scales, we need you to go on a diet or.. How would that work?

HWM11: Well I think perhaps, perhaps they could have made an issue of it and said… I don't think anybody's ever said to me that atrial fibrillation, you know the symptoms of it and the occurrence of it can be limited by being a lot slimmer. You know, that was never said by a cardiologist, as far as I'm

aware. Um. You know. I think a direct sort of lecture if you like, by a professional.. and for them to say.. say if they were to say "we want you to lose weight and we'll give you this target, do you think you could lose this much by such and such a date?" and then monitor it, um, people respect the opinion, don't they of, professionals, and so if you thought that was what you had to do, then you would do it. And I think it's because people don't that they then sort of continue as they are - myself included probably – and therefore we're wasting lots of people's time in more and more shockings, and things.

RB: Yeah, so do you think it needs to be a bit more black-and-white, the communication about.. you need to lose weight *because*

HWM11: Yeah, I think so 'cause I don't think it's ever been explained directly to me that this is happening due to your weight, if you see what I mean, no-one's ever said that.

RB: Yeah, I do think some cardiologists and other doctors shy away from having those conversations with patients because they're worried about offending people

HWM11: Well sometimes you've got to be cruel to be kind though haven't you?

RB: And it doesn't sound like you personally would be offended if someone sat you down and said ok, we need to talk about your weight in a.. for health reasons

HWM11: I think a lot of people would like to lose weight and feel better about theirselves but they need, they a reason to do it. And you can always find yourself a reason *not* to do it. Which is usually oh, I'd rather eat this bag of crisps. Y'know. But if someone tells you, you have to do it or something will happen, then you'll do it. You, you would.. everybody would do it I would think, because that is a direct, you know direct direction from a professional. And in fact, if it's the consultant even that's someone who you would not doubt their opinion even would you, at all.

RB: Yeah. The boss.

HWM11: Yeah

RB: Alright [name], I'm gonna let you go, thanks ever so much for talking to me.

HWM11: That's alright, we stayed in the car for you!

RB: I'm really honoured! Thank you so much. I've just got a couple of questions I've got to ask you for house-keeping and then I promise I'll let you go. The first is your..

HWM11: That's jolly good yeah. I like hoovering.

RB: ..your ethnicity

HWM11: My ethnicity? I'm white British.

RB: White British. And what's your highest level of education?

HWM11: Um, surprisingly, PGCE I think. I've got a degree but it's a post-graduate so I'm a BA Honours and PGCE

RB: That doesn't surprise me at all, you seem like a very intelligent bloke

HWM11: I'll have that! If only I made more intelligent choices of my food!

RB: And by profession you're a teacher, yeah?

HWM11: I am yeah. And also a mechanic by profession

RB: A mechanic and a teacher?

HWM11: Not, not any more, not any more. But yeah.

RB: So if I were to describe you in the study as a teacher, that would be ok?

HWM11: Oh I think you should yes.

RB: And then the last question is, I'm asking everybody to give me a name to call them by that isn't their own name..

HWM11: Haha, really?

RB: ..because I don't want to refer to people as numbers but I don't want people to be recognisable either, um because.. some of the doctors that I work with are the doctors that treat you, and they might read this study and know.. not that you said anything bad but somebody could say something that… it needs to be confidential is what I'm trying to say. So what I'd like is..

HWM11: Yeah we don't want them saying "oh that's old fatty, isn't it"? [laughs]

RB: "Oh we know who that is, oh give him an extra shock"

HWM11: "That's old porky that is" yeah. No um. What you want a name? I'm gonna be one of the cats. I'll be Alfie

RB: Alfie?

HWM11: Alfie's actually my daughter's dog. I'm gonna be Alfie.

RB: Alfie's a brilliant name, that's absolutely perfect, I like the name Alfie

HWM11: We call him Alfie Barker

RB: Alfie Barker!

HWM11: 'Cause he barks all the time.

RB: That's perfect. Thanks ever so much. What I'll do now is over the next few days I'll type this interview up, it usually takes quite a few hours to type them up, it's quite a long process. And then I produce a summary, and I'll phone you and read the summary back to you

HWM11: No problem

RB: It takes about 5 minutes, it's much quicker, just so you can check I've got what you're saying right and I'm not making things up or misinterpreting what you've said to me. Is that ok?

HWM11: Ok, I'm sure you haven't

RB: But if there's anything else that you want to change or add or you think of anything else that you think I wish I'd said that, you can add it in

HWM11: No I think that's fine. I've made a note on the you know the Kardia thing, I made a note when they started the digoxin. I haven't as yet made a note when they upped it to double the dose. If they do stuff like that, do you want me to record on there when they've done this shocking as well?

RB: Yes that would be really helpful actually. Not for this study but for the [other study name] study that the device is for.

HWM11: Yeah, that 's what I thought yeah.

RB: That'd be really helpful if you just keep a note of any dose changes and the date they happened, you'll make (research nurse name) very happy

HWM11: Right, jolly good. Have a nice night

RB: Yes you too, have a nice weekend

HWM11: I'm just gonna have a couple of sips of water I think, this weekend

RB: Yeah, couple of sips of water, maybe a lettuce leaf.

HWM11 No I don't like lettuce

RB: A Ryvita?

HWM11: I'm gonna suck a bit of gravel. Yeah I've got Ryvitas [wife says "You won't touch 'em! They're like cardboard!"] Yeah that's true. Never mind, I'll.. don't you worry. I shall weigh myself today and you'll be surprised.

RB: Alright I might see you on [date], alright, thanks [name]

HWM11: Not if I turn sideways you won't!

RB: Ok, see you

HWM11: Cheers, bye bye

[ENDS]