**Participant 17 Interview**

**EX-FRAIL CKD Trial**

AN: This is Dr Andrew Nixon Clinical Fellow in Renal Medicine conducting an interview for The EXFRAIL CKD trial IRAS ID 244772 on *[date deleted]* with participant I.D. 17. Well firstly again thank you so much for taking part in the study and taking part in the interview today. As I said it will be just a broad discussion about your experience of the study.

PT: Yeah.

AN: So I guess firstly I'd ask how have you found the study? [00:00:47] How's it been for you?

PT: Very good. I've found it very interesting. And it's helped me a lot in getting my strength back up cos I'd got very weak.

AN: Right.

PT: And this has helped me a lot really.

AN: Right. [00:01:08] So what things have you noticed?

PT: Erm getting out of a chair easier err walking upstairs easier.

AN: Right.

PT: Erm walking on the flat with my walking stick.

AN: Yeah.

PT: I can go a bit further than I used to be able to.

AN: OK.

PT: Maybe about another five or ten metres. About five-eight metres more than I used to do.

AN: Yeah.

PT: So yes I found it very…

AN: Has it influenced your confidence do you think?

PT: Yes. Yeah.

AN: In err…

PT: It’s it's it's made me more active than I was before. I erm…

[00:01:49]

AN: What in addition to doing the exercise?

PT: Yeah.

AN: So why is that?

[00:01:56]

PT: I don't get quite as breathless as I used to.

AN: Right. Okay.

PT: Erm it a, and I find it easier to move about than I did before.

AN: Yeah.

PT: Because I was struggling erm I was having to use my walking stick in the house, which now I don't need to.

AN: Right. [00:02:16] OK.

PT: Yeah.

AN: OK, fantastic. [00:02:20] Erm thinking back and you might not recall this, I completely understand, it is a while ago now but I'm thinking back to when you were first approached about the study. [00:02:33] What made you want to get involved?

PT: Discussions with my family.

[00:02:41]

*[Excerpt deleted to maintain confidentiality]*

AN: Right, OK.

PT: And they were proved right because it has done me good.

AN: Right. [00:03:02] So it was it was their advice that…

PT: Yeah yeah.

AN: You thought OK I'll give it a go?

PT: Yeah.

AN: Fantastic. [00:03:10] Did you think the information we gave you at the beginning was sufficient for or did you have some reservations about it when you first or do you not remember?

PT: It intrigued me.

[00:03:24]

AN: Yes.

[00:03:27]

PT: And after my first meeting with you it laid any fears or worries that I had about it. As I say, I was intrigued with it.

[00:03:41]

AN: My concern sometimes is about the language we use and can it put people off? So, I think sometimes even the word exercise…

PT: Yes.

AN: …can put people off. [00:03:50] What do you think about that?

PT: With the other exercises that I do, I think that no it doesn't. Because…

AN: Yeah.

PT: …I'm used to the word and I'm used to doing it.

AN: Yeah.

PT: But I must admit I found it very very beneficial, very beneficial.

[00:04:10]

AN: So, when when you you first were approached about being in an exercise study did you think the exercises would be the type that you were doing or did you have a different image in your mind of what you might be doing?

PT: With doing it at home [00:04:23] it would be completely different to what I do at the gym.

AN: Yes.

PT: And sure enough they have been.

[00:04:30]

AN: Mmm mmm.

[00:04:35]

PT: And err although I found it at the beginning a lot of breathlessness in it. I’ve gradually overcome that. I still certainly the one in the chair pushing up I still get a bit breathless with that but not as much as I used to.

[00:04:50]

AN: Yeah.

PT: And err the others don't seem to bother me nowadays.

AN: Yeah.

[00:05:00]

PT: That part of it’s gone.

AN: Mm hmm.

PT: So yeah. As I say it’s been good.

AN: Good. [00:05:08] Thinking about language again and how we let people know about this study and get people to hopefully be interested in being involved. One of the… one word that we sometimes use which means something different to health professionals to what I think that it means to the general public is this word frailty. Do you think… what do you think about that word? And the language? And what does it mean to you?

[00:05:39]

PT: That's the thing that intrigued me. That word.

AN: Yeah.

PT: When I first decided to come on it. Because yes, I was frail and I was getting worse, even though I do the exercises that I do. Erm I was beginning to not get beneficial benefit from them. But since I've been doing these, the two combined…

AN: Yeah.

PT: They have helped me an awful lot. Yeah.

[00:06:16]

AN: So actually, that word for you could you could identify with that?

PT: Yeah.

AN: And you thought Okay yeah this is…

PT: Yeah yeah.

AN: Okay. That's interesting.

PT: Yeah.

AN: That's helpful. Of course, when you came on that that first visit. We erm we randomly assigned, we had this randomization process. And of course, you may have been randomized to not doing exercise. [00:06:41] How would you have felt about that?

PT: Erm from the outcome that *[inaudible]*… [00:06:49] I'd have been disappointed.

AN: Yeah.

PT: ‘Cos I’d expected to get some benefit from it but I didn't expect to get as much benefit as I have.

[00:07:00]

AN: Yeah but say if way back three months ago, and if we’d have done those first visits and said to you actually you've been randomized not to exercise, would you been happy to continue on in the study or do you think you'd have said you wouldn't have been happy? What would you…

PT: Oh I would have been happy to carry on, yes.

[00:07:19]

AN: Sorry?

PT: Yes. I would have been happy to carry on.

AN: So you would have come back for the final visit? [00:07:24] OK that’s good to hear. But it sounds like you were pleased that you were…

PT: Yes.

AN: …involved in the exercise group?

PT: Yeah. Yeah.

AN: It's always interesting to… I’ve had people say that they were pleased that they weren’t in the exercise group and others say that they were so erm no that’s [00:07:43] good to know.

PT: I’ve found it, I really found it very helpful, very very beneficial to my overall health.

[00:07:53]

AN: Yeah, just your physical health or also affected your mental health or your…

PT: Yeah I think it has. I think it’s made me more content with my life.

[00:08:07]

AN: Yeah right. Okay.

PT: Yeah.

[00:08:09]

AN: What about energy levels is it had any effect on them?

PT: Yes.

AN: Right. OK

PT: Yeah.

AN: In what way?

[00:08:14]

PT: Erm I can do more than I used to able to although in saying that I do… some days I get very fatigued.

AN: Yeah. [00:08:28] Is that because of the exercises do you think?

PT: No, it is more or less on the days that I'm not doing the exercises…

AN: OK.

[00:08:34]

PT: …for some reason or another. But I've struggle with, ever since my wife died I struggle to sleep.

AN: Right.

PT: For some reason or other erm I still do that erm and I think it could be that…

AN: Yes.

PT: …more than anything else than not sleeping through the night.

AN: Do you tend to sleep better if you have exercised or have you not noticed a difference?

[00:09:02]

PT: No not really. No.

[00:09:06]

AN: OK. But would you say your overall energy levels have changed over the three month period or are they much the same?

[00:09:13]

PT: No, I think I've got more energy.

AN: More energy? [00:09:16] Ok. Good good. [00:09:19] When you came for that first visit and obviously when you have been today we've done some physical assessments, [00:09:26] what do you think of those? How did you find them?

PT: A lot easier this time.

AN: A lot easier this time?

PT: A lot easier. [00:09:33] Certainly the balance one. I found it, although you know I was wobbling a bit, I did that better and I think I wasn't quite, I wasn't as breathless or really breathless at all when doing the chair one.

[00:09:55]

AN: Yep. Have you noticed a change in your balance over that period or is it you haven't really noticed until you've done that?

[00:10:04]

PT: No, I'm haven’t really noticed it.

[00:10:07]

AN: Do you think, were the physical assessments easy enough to perform?

[00:10:12]

PT: Yes.

AN: Or do you think they were too difficult?

[00:10:15]

PT: No no, I think. They were just just about right.

[00:10:18]

AN: And were the instructions clear?

PT: Yeah.

AN: OK. Whilst you're performing the assessments, did you ever feel uncomfortable or unsupported or under pressure or any anything like that?

[00:10:31]

PT: No no, not really. I found it all very helpful and very *[inaudible]* if I did start wobbling you were both stood there and wouldn’t let me fall over.

AN: Yeah.

PT: Because certainly the last one with your foot in one of the others.

AN: That balance test?

PT: That balance test thing, that was a bit err…

[00:10:59]

AN: No, it's good that you felt supported during that. What about the questionnaires that you're asked to complete. How did you find those?

[00:11:09]

PT: Alright. Yeah. Yeah. [00:11:11] Very simple questions with easy enough tick boxes to answer.

[00:11:18]

AN: Did you did any of the questions, [00:11:21] did you think ‘oh this seems silly or inappropriate’ or did it make you feel uncomfortable in anyway?

[00:11:27]

PT: No no no. It seemed all relevant to what's been going on for the last three months.

[00:11:34]

AN: And did you think we asked too many questions?

PT: No.

AN: No?

PT: No.

AN: Did you find… I think there were three questionnaires I asked you to complete. Did you feel it was difficult to concentrate or you were getting fatigued doing the questions?

PT: No no. They were alright.

AN: And again did you feel like that you had a clear instructions and…

PT: Yes. [00:12:02] Yeah. The instructions you gave me and certainly reading the top of each one, it was very precise on what I had to do and what to look for when I was looking at the answers.

[00:12:17]

AN: Okay, good good. [00:12:18] So from your point of view do you think there's anything we should be doing differently either… if we go on and do a big study, is there anything you think we should be doing differently with the questionnaires or with the assessments from a participant point of view?

[00:12:33]

PT: No. I found them all very useful and very informative on the questions and what the answers could be or were down to do.

[00:12:50]

AN: You felt it was clearly explained?

PT: Yeah yeah

AN: OK, that's good. [00:12:54] Okay. [00:12:58] Erm. We obviously, our physiotherapist erm obviously educated you on the exercise program and you came back for an additional session didn’t you?

PT: Yeah.

AN: How did you find those education sessions?

[00:13:14]

PT: Very helpful. Yeah.

AN: Yeah.

PT: XX, that did it, was very patient with you and explained everything in very good detail so that you knew exactly how to do it and what to look for when you were doing it.

[00:13:32]

AN: Yeah.

[00:13:34]

PT: And what, if you got to your limit, [00:13:39] you know, she was like stop and rest and…

AN: Yeah.

PT: …take your time and I found that very good.

[00:13:46]

AN: Did you feel like the this, where we've done things, the environment was suitable for what we're doing?

[00:13:56]

PT: Yeah. Very good.

AN: And did you feel like you had enough time with XX?

PT: Yeah.

AN: We obviously did the exercise session at the same time as your first visit.

PT: Yeah.

AN: Do you think it would've been better to split that up? It was a long visit wasn't it in the end, wasn’t it? It probably would have been a few hours.

[00:14:16]

PT: No no no. It was it was just right.

AN: Yeah?

PT: It wasn't rushed and everything was fully explained. [00:14:27] Yeah, I found it very helpful.

AN: So, did you go away from those visits thinking ‘okay I know what I need to do a home now’?

PT: Yes. Yes.

AN: And you felt you felt comfortable and confident to…

[00:14:37]

PT: Yes. Yeah. Very confident, very comfortable at doing them. And as I say, they were well explained and I knew what I had to do and what have you.

[00:14:49]

AN: What do you think of the guidebook that you were given?

[00:14:52]

PT: Very helpful.

AN: Yeah

PT: I used to every time.

AN: Right. OK.

PT: I didn't… [00:14:59] erm [00:15:00] how can I put it, not trust erm, I used it as a guide, every time, so I knew that what I had to do, I did…

AN: Yeah.

PT: And I found it very helpful.

[00:15:14]

AN: So, were the instructions clear…

PT: Yes.

AN: …and that?

PT: Yes.

AN: And were the pictures the helpful?

PT: Yes.

AN: Right. Okay.

PT: The only one that would have anything, was the last one where I was doing the marching.

AN: Yeah.

[00:15:28]

PT: Up and down.

AN: Yeah.

PT: Erm it's not quite thing that you do. You lift your left leg and then your right and that's one.

[00:15:39]

AN: Yeah.

PT: Where you could’ve misinterpreted doing one, two, three, four.

AN: So you think that could’ve been a bit clearer?

[00:15:47]

PT: Yeah. I must admit the first time did it, I thought that's wrong. I did the first set of 10 and I thought [00:15:54] that's wrong because all the others are, it's your left leg and your right leg, each one.

AN: I’ll have to look at the wording of that.

PT: And I must admit, the first time did it, I did one, two, then I thought, I’d done the ten, then I thought no that's wrong. So it… erm, whether it was me or not or whether it is just the thing I'm not too sure. But it was only when I did it then I thought ‘no that’s not what you do with all the others’, you know, left and right and that's one.

[00:16:32]

AN: Is there anything you think else you think we could've done differently either with the guide book or the education sessions that you had?

[00:16:40]

PT: No. No. It was all fully explained. And as I say, the booklet is very helpful.

[00:16:49]

AN: OK. Now the next question I have here is- were you able to perform the exercises regularly at home? Obviously…

[00:16:53]

PT: Yeah.

AN: …I know the answer to that question, which you were very diligent I think performing the exercises.

PT: Yeah.

[00:17:01]

AN: Is there anything that helped you to exercise or motivate gave you motivation to do it? Why why why were you so kind of disciplined?

[00:17:13]

PT: I think it was to get erm I used to be very active, especially at work and this like 10 years since I retired erm I've gradually gone down and I’ve been trying to get it back up again and because I enjoy going bird watching and I enjoy going out in the countryside and that's curtailed quite strongly because I've just not felt with enough energy to do it. And nowadays I'm getting that back. In this last three months, it's beginning to build back up again.

AN: Right. [00:17:49] Okay. Good. Good. [00:17:53] So we did touch on this. So it was, how the exercises made you feel? So, obviously it sounds like you’re being able to do a bit more?

PT: Yes. Yeah.

[00:18:05]

AN: But in terms of how you how you felt in yourself?

PT: Erm, I felt more confidence and more alert if you will.

AN: Mmm.

PT: Erm. Yeah. It's been it's been, as I say I found it very helpful indeed, [00:18:25] with me overall.

AN: Did a family member or friend support you doing the exercises?

PT: Yes.

[00:18:32]

*[Excerpt deleted to maintain confidentiality]*

[00:18:59]

AN: So, they were they were pleased that you were doing it?

PT: Yes.

AN: Did you always do the exercises by yourself though or did you…

PT: Yes.

[00:19:05]

AN: OK, yeah. [00:19:08] So how did you, how did you feel about doing those exercises by yourself at home? Did you feel…

PT: Very comfortable.

AN: OK.

PT: Yeah. Very comfortable. [00:19:19] The thing of being able to sit down and rest in between them and stuff like that, it was it was good.

[00:19:31]

AN: Did you feel safe doing them at home?

PT: Yes, yeah.

AN: Do you think for a study like this, having exercises that people can do at home is better or worse than say having exercise classes that people could come to attend? What are your thoughts on the two?

[00:19:51]

PT: Personally, I found that it better being able to do it in the privacy of my own home.

AN: Right.

PT: And doing them at my own pace.

AN: Yeah. Have you been to classes before at the gym?

PT: Yes.

AN: How did you find them?

PT: Hard work.

AN: Right.

PT: Yeah. I used to go to classes at the gym and I always, well I stopped doing them, I only did around three or four because to me it didn't appear for my age.

AN: Right.

PT: And my physical, you know, they were all, I wouldn't say they were all younger than me but they were all quite fitter than me and they didn't really go into helping me with what I wanted to do.

AN: Yeah.

PT: Where these, as I say, I could do them at my own pace and [inaudible] most of the times I did them in mid-afternoon but once or twice I did them a bit later on in the day if I’d been out for the day and I hadn’t done them, I did them a later on. So I found that very helpful.

AN: Ok so it worked better for you?

PT: Yes, a lot [00:21:10] better for me.

[00:21:14]

AN: How did you find the erm the weekly phone calls we were doing? Were they helpful?

[00:21:19]

PT: Yeah.

AN: Or a bit more of a nuisance?

PT: No. No, I found them very helpful. [00:21:26] Your comments that you made when I did them were encouraging. Yeah. Yeah. I found it as I say I found the phone calls very encouraging. And it kept me on my toes that they were there and I had to do them and stuff like that, although, you know, I did them every, at least every other day but once or twice it would be two days before I did them. I changed it about so that I didn't find it monotonous or anything.

AN: Yeah. In what way do you change it about?

PT: Well erm when you look at the days sometimes it be two days between.

AN: Oh I see.

PT: Or it would be one day. Sometimes it'd be in the afternoon. The odd times it would be a bit later on.

AN: Yeah.

PT: Just after tea or something like that so I didn’t erm...

[00:22:26]

AN: How did you find the… so I think we progressed you with certain of the exercises. [00:22:34] I think one of them we went and made it a little… we asked you to do I think ten of the repetition of the exercise 4 and said OK let's cut it back.

PT: Yeah.

AN: How did you find the changes that we asked you to do?

[00:22:47]

PT: Very good. Certainly the standing up in the chair when I did 10 I found that very very difficult.

AN: Would you say that was the hardest one for you?

PT: Yes yes. It's always has been and dropping it down to five was very helpful for me. Very helpful indeed. And then when we put it back up to seven. The first couple of times I was [exhales]. But then it got easier. And I wasn't getting, that was the only one that I really really got breathless with.

AN: Yeah.

PT: And when it was ten it was it was quite bad.

[00:23:30]

AN: Do you think when we think about the exercise program that's maybe something we should be looking at changing so asking people to go away and do ten straight away, do you think that’s…

PT: Yes.

AN: Do you think that’s a bit…

[00:23:46]

PT: Yes. It was for me.

AN: Yes.

PT: I don't know if it would be for everybody but it certainly was for me. That first week when I did the 10 those three times it was hard work.

[00:24:00]

AN: Yeah. Were there any of the other exercises that were difficult for you?

[00:24:08]

PT: No no, not really. I think they were all more or less the same. Certainly one or two of the leg stretch ones and things, I used to get calf strains at the back.

AN: Would you?

PT: But within quarter of an hour, 20 minutes of been sitting doing it, it’d disappear.

AN: When you say calf strain what do you mean by that?

[00:24:27]

PT: My calfs were tightening up.

AN: They were just a bit tight?

PT: Yes.

AN: Were they cramping?

PT: No no, not quite as bad as that.

AN: They just a felt a bit as though they've been working?

PT: Yes. Yes.

AN: But you say that would last for?

PT: Quarter of an hour 20 minutes and then it’d stop.

AN: And would it bother you that next day or anything like that.

[00:24:44]

PT: No no no no no no. I would just that, like quarter an hour 20 minutes after I'd done the exercises where you could still feel them being taunt and tight.

[00:24:55]

AN: Did it affect your ability to do your normal everyday things the following day after you've exercised or the same day?

PT: No, never [inaudible]. It was…

AN: Good.

PT: Yeah

AN: And did… when we were making certain exercises more difficult, did you think we were doing things too quickly or was it, did you feel under pressure?

PT: No, I was I was ok. There was no problem at all.

[00:25:21]

AN: Okay. [00:25:22] Because I think some of them we did over the phone didn't but we? But we obviously also asked you to come in for an extra session so XX could, our physio could assess you doing the movements. Did that all work?

[00:25:37]

PT: Fine.

AN: Yeah.

PT: It was there was it was it was really fine erm well explained.

AN: OK.

PT: She showed me what to do and it was really good.

AN: Good. [00:25:50] Did you feel like it was easy enough to get hold of us if you needed to?

PT: Yes. [00:25:55] Yeah.

AN: Yeah?

PT: Yeah.

AN: Good. [00:25:57] So you never felt you that you were isolated?

[00:26:00]

PT: No. No.

AN: Okay good. Well we've gone through that rather quickly but then I think your comments have been really erm very helpful and there's some some interesting points you made that for for me to think about how we could look at changing things but it sounds like it's been an overall a positive experience.

PT: Very positive, very positive indeed.

AN: Yes.

[00:26:33]

PT: Yeah. As I say, I intend to keep it up after I’ve finish this because it's made me feel so much better.

[00:26:44]

AN: Yeah.

[00:26:46]

PT: And they’re not, now that I'm getting used to them, they're not too difficult for me to do.

[00:26:53]

AN: Yeah.

[00:26:56]

PT: You know it's like half an hour three times a week.

AN: Yeah.

PT: It's been very good and I've found so much benefit out of it.

[00:27:07]

AN: One thing I forgot to ask actually was about the diary and recording. How did you find doing that?

PT: All right.

AN: You didn't…

PT: It's easy enough to follow and stuff like that.

[00:27:17]

AN: And those, when we were asking you to rate your exertion, you know those exertion scores was that tricky or did it…

[00:27:24]

PT: The first couple of times. Yeah. I'm thinking yeah am I doing the right thing here but then yeah towards when I got used to it erm it was quite straightforward. Yeah.

AN: Ok do you think there is a different way... [00:27:43] because for us it's difficult when we're on the phone and we’ve not obviously watched you exercise, we need to get an idea. We want you to be working hard enough that it's training, you know, it’s training your muscles but not too hard. It's trying to assess that in some way. [00:28:00] Do you think there is a different way we could do it or do you think…

PT: For me I found it, [00:28:05] once I got used to it, I found it very easy to do it and it was pretty straightforward. But as I said at first two or three times it was a bit difficult to assess and I kept having to look back on the forms on your coloured chart to see that’s that one, that’s that one. Yeah.

AN: Yeah.

PT: But once I got used to it was…

AN: Did you then use it to keep track of how hard you were working?

PT: Yes.

AN: Or were just doing it for us, if you see what I mean?

[00:28:43]

PT: No, I did I did it for my own benefit.

AN: OK.

PT: To see how I was because like when you've changed it, changed them to make them a bit difficult, the scores went up.

AN: Yeah.

PT: Because I was finding it more difficult to do until I got used to them and then it came back down again.

[00:29:08]

AN: So, again somethings popped into my head that we were speaking earlier about and so I said to you look if you'd have been randomized not to do the exercises and we just said ‘Okay thank you, we'll see you again in three months’ time’, you said ‘I would’ve still come for the final assessments’. [00:29:28] Can I ask why you would have still come?

PT: To see if it I’d got any benefit out of it.

AN: Even if you weren't doing any exercises?

[00:29:38]

PT: Yes. Yeah.

AN: Do you mean to to see how how your…

PT: Yeah.

AN: …how you'd have done on any of the tests?

PT: Yeah. Yeah.

AN: Yeah. [00:29:46] Okay. [00:29:50] What are your thoughts on in general about people who are a bit older with kidney disease exercising? What are your thoughts on that?

[00:30:01]

PT: I think it's useful. Erm, I must admit I was although I exercise through the gym, for some reason or another I was going downhill and not really getting the benefit out of going but when I started doing this I've gone back up again.

AN: Ok.

PT: And I'm going back up again.

AN: Yeah. [00:30:25] So do you think that… obviously part of the reason why we’re doing this study is, so hopefully we can do a bigger study where we can look at the benefits of it and if we can make, there's a lot of ifs and buts, but if we can demonstrate benefit then maybe we can convince people who decide on how money is spent in the NHS that we should be offering a service like this to our patients with kidney disease, an exercise service. Is it something that you would you would take up and get involved with?

PT: I think so yes, yeah.

AN: Or is it, [00:31:03] do you prefer just to continue doing things by yourself?

[00:31:11]

PT: It depends really on how it was run.

AN: Yeah.

PT: And what it, but certainly doing it at home as I said before I found it very useful and stuff like that. And I think it would benefit a lot of patients more patients if they took it up, to be quite honest with you because I really found it…

[00:31:35]

AN: And what kind of what, when you say benefit., what, where do you think you'd benefit the most or how would you?

[00:31:42]

PT: It would give you a purpose erm to to do it.

AN: Yeah.

PT: Because as I said before, I’ve found the health benefits of it very enlightening. And I can, I felt the benefits.

AN: Yeah.

PT: And it's been it's been very helpful for me.

[00:32:07]

AN: OK, good. I'm really pleased about that. I really am. No, it's been an absolute pleasure. [00:32:12] It really has. Is there, before I stop the recording, is there any other comments you'd like to make about the study or…

[00:32:19]

PT: No, I think I've said everything. As I say, I found it very helpful and I'm certainly fitter than, I think I'm fitter, feel fitter than I did before, three months ago when I started it.

AN: Yeah.

PT: I'm certainly, yeah, as I said, I felt the benefit of it.

AN: Fantastic. Well thank you very much. I’ll end the recording there.