**Participant 16 Interview**

**EX-FRAIL CKD Trial**

AN: This is Dr Andrew Nixon Clinical Fellow in Renal Medicine conducting an interview for The EX-FRAIL CKD trial on *[date deleted]* with participant ID 16. Right, firstly thank you for agreeing to take part in the interview. I thought firstly it would be helpful just to ask you your general thoughts on your experience of the study?

PT: I thought it was very good, it’s strengthened my legs, yes, nice experience, yes.

AN: OK. So, you feel it's improved the strength?

PT: It has improved the strength of my legs. Yeah, I think so.

[00:01:03]

AN: And what…

PT: It has improved my walking.

AN: Improved your walking?

PT: It has, yes. My daughters have noticed the improvement.

AN: OK.

PT: They have said about it. Yeah.

AN: What improvement has there been?

PT: I can walk further.

AN: OK.

PT: And quicker than what I have been doing.

AN: So how far can you walk now for example compared to before you started?

PT: I don't know. I don’t know how…

AN: Just in minutes? [00:01:35] I guess if you could go out for…

PT: I can go out for about half an hour I would say now.

PT: Yeah.

AN: Could you have done that before?

PT: I couldn’t have done that before. No.

AN: How far would you have walked for?

PT: About five minutes, 10 minutes.

AN: Really?

PT: Yeah.

AN: And what limited you before?

PT: I just don't have any strength in my legs.

AN: OK.

PT: They’re just really weak.

AN: Did you just get tired?

PT: Yeah. Yeah.

AN: OK.

PT: Yeah.

AN: Well I'm delighted to hear that. That's really really great.

PT: It is.

AN: OK. Well I've got a few questions to ask, if that's OK?

PT: No problem.

AN: Erm I guess firstly I'm always interested to know why somebody decides to take, take part in the research in the first place. For you what made you want to take part?

PT: I’m happy to do anything that will help, you know, other people.

AN: So, it was the idea that it might help other people with kidney trouble in the future?

PT: Yeah. Exactly. Yeah.

AN: Did you also think there might be some benefits for you or did you not know?

PT: Exactly. I thought try and strengthen my legs. They have been weak since right from the beginning when I was in hospital. I was in hospital for four weeks and couldn't put my feet to the floor when I got the myeloma.

AN: How long ago was that now?

PT: Four years. Four years.

AN: Why couldn't you put your feet to the floor?

PT: Because of my back. It were my back and they wouldn't let me put my feet to floor. It just weakened all my legs.

AN: Yeah.

PT: And since then I haven’t been able to walk very far. It has helped, all this exercise has helped.

AN: Good.

PT: With my legs.

AN: That's really good to hear.

PT: It has.

AN: [00:03:34] Do you recall the information that we gave you to begin with? You know the information sheet and things? Do you recall how you felt when you when you got that? Did it make sense to you or did you think…

[00:03:49] PT: Yeah it did. Yes.

AN: [00:03:54] Were you put off by the idea of the word exercise for example?

PT: No. Because before I started being ill I used to go to the gym every day.

[00:04:02]

AN: Did you?

PT: Yeah.

AN: So, exercise was…

PT: Yeah.

AN: What did you used to do in the gym?

[00:04:08]

PT: The treadmill.

AN: Yes.

PT: And the rowing machine. I used to do that and the bikes.

AN: Yeah.

PT: Yeah. Used to do all that.

[00:04:18]

AN: Were you put off by the… or what did you think of the name of the study? [00:04:26] So we called it The EXFRAIL CKD trial. Now that word frail, did that did that put you off or…

[00:04:33]

PT: No, not really.

AN: No.

PT: ‘cos I felt frail, I feel frail myself.

[00:04:38]

AN: What does frail mean to you?

PT: Not being able to do much.

AN: Yes.

[00:04:44]

PT: I haven’t got much strength in my arms, opening drawers and different things like that.

[00:04:51]

AN: So, the use of that word didn't put you off…

[00:04:56]

PT: No.

AN: … taking part?

PT: No.

AN: Good. Good. OK. [00:05:05] So, obviously you came for the first visit, and during that visit you were, we randomly, using a computer software, we randomly assigned you to exercise.

PT: Yes.

AN: But of course there could have been a chance that you got randomized to not do exercise.

PT: Yes.

AN: How would you have felt if you had got randomized to not doing exercise?

PT: I don’t know really, erm, I don’t know, erm.

[00:05:35]

AN: Do you think you would have been happy to continue on in the study?

[00:05:51]

PT: Yeah. Yeah.

[00:05:54]

AN: You would have been… You would have been happy to come for this final visit?

PT: I would, yeah.

AN: Would you have been disappointed?

PT: Not to do it? Yeah, I would.

AN: You would have been?

PT: Yeah.

AN: But you, do you understood why there were the two groups?

PT: Yeah. Yeah.

AN: What was your understanding of why we had two groups?

[00:06:17]

PT: Just to see whether you could do it or not. You know whether you could do the exercises.

[00:06:24]

AN: Yeah. And obviously, this study we're doing at the minute is to see if we if the exercise can be done and are safe to do and the study can be done. But we are hoping if that if it is possible to do all that, we can do a bigger study where if we have a bigger study to say whether the exercise program is of benefit to somebody…

PT: Right.

AN: … you of course need to compare it against people who are not doing it. Do you see what I mean?

PT: Yeah.

[00:07:04]

AN: And so that's why we have the two, the two groups.

[00:07:08]

PT: Yes.

AN: Erm, OK. The physical assessments that we've done at the two visits, we had, obviously when you first came and when you've come here today we've done the walking tests, the sit to stand test, the balance sets and the grip strength tests. How did you find those?

PT: Okay.

AN: Did you feel like you were being asked to do too many tests or not?

[00:07:38]

PT: No no no. It was alright.

AN: OK.

PT: Yeah.

AN: Did you find them easy to perform?

PT: Yes.

AN: Did they make you feel uncomfortable at any point or did you feel unsupported?

PT: No.

AN: Or under pressure?

PT: No.

[00:07:58]

AN: OK. [00:08:01] So you don't think we were asking you to do too many?

[00:08:04]

PT: I don't think so. No.

[00:08:06]

AN: OK. OK. [00:08:09] And what about the questionnaires that you asked to complete, what did you think of them?

[00:08:17]

PT: They were all right. Yeah.

AN: Do you feel like, [00:08:24] well first off were they easy enough to perform? Did you find them difficult?

PT: No, they were easy enough to fill in.

[00:08:32]

AN: Did you feel like any of the questions were inappropriate or made you feel uncomfortable?

[00:08:40]

PT: No. No.

[00:08:44]

AN: There were quite a few questionnaires that we asked. Do you think there was too many?

[00:08:50]

PT: No.

[00:08:52

AN: You didn't find that was…

PT: No.

AN: OK. Because there were quite a few that you had to complete, did you have difficulty concentrating or did you find any issues with the amount of time it took to fill in?

PT: No.

AN: OK. And did you feel that you were supported?

PT: Oh yes. Yeah.

[00:09:18]

AN: OK. So, if we were to go on and do a bigger study, do you think there are any changes that we should be making to the assessments that we've asked to do? Both the physical ones and the questionnaires?

[00:09:30]

PT: No, I don't think so.

[00:09:32]

AN: Yeah?

PT: I think everything was sufficient. I think.

[00:09:36]

AN: You think it's OK?

PT: Yeah.

[00:09:41]

AN: OK. Do you think there's anything that we could change in how we how we approach patients and how we discuss with them the study that might encourage people to or might make patient people more likely to take part?

[00:10:01]

PT: I don’t think so. You did everything right.

[00:10:09]

AN: OK. So how did you find the exercise program? What did you think of it?

[00:10:13]

PT: I thought it were alright.

AN: Yeah.

[00:10:15]

PT: It were hard at first but as you get into it, it becomes easier.

AN: OK. What do you, you obviously had that first education session. [00:10:28] In fact you came for second one as well, didn’t you?

PT: Yes I did, yes.

AN: What were your impressions of that education section? What did you think about it?

[00:10:38]

PT: I thought it were alright. Yeah.

[00:10:43]

AN: Did you did you feel, was the environment OK?

PT: Yes.

AN: The help the physiotherapist gave you in the education…

[00:10:57]

PT: Yes. She's been very nice. [00:10:59] Yeah. Very helpful.

[00:11:01]

AN: Do you think you were given too much information too quickly or were there was everything explained up front?

PT: Everything was explained.

AN: So did you…

PT: What I had to do today and everything.

AN: Did you go away on that day understanding?

PT: Yeah.

AN: OK. What did you think about the exercise guidebook?

[00:11:22]

PT: Erm helpful. [00:11:25] Yes it was.

AN: What was particularly helpful?

[00:11:30]

PT: How it explained what you had to do and everything? Yeah.

[00:11:35]

AN: What did you think of the photos?

PT: OK.

AN: Yeah.

[00:11:39]

PT: Yeah.

AN: Was it useful to see?

PT: It was. Yeah. [00:11:43] Yeah.

[00:11:49]

AN: Do you think the exercise guidebook was perhaps a bit too big or too long? [00:11:54] Or do you think…

PT: No no. It explained what you had to do. It showed well the pictures showed you.

AN: Can you remind me when you got the exercise guidebook [00:12:07] did we give you, for each of the six exercises, did we also give you that the four stages for each of them?

PT: Yeah.

AN: We did, yeah. Because obviously that was a lot of information.

PT: It was, yes.

AN: Do you think we maybe should have just given you the ones, the exercises, that you were going to start with rather than giving you all the different progressions?

[00:12:29]

PT: No, I thought it was alright.

[00:12:31]

AN: You thought it was ok. Is there anything you think we could have done to make that session more useful or more helpful or enjoyable?

[00:12:51]

PT: I think everything…

AN: Yeah.

PT: … you did everything right I think.

[00:12:56]

AN: And how… [00:12:59] How did you feel about the physiotherapist teaching you things? Would you have preferred someone else to do it, say as a nurse or doctor?

PT: Oh no, she was alright, yeah.

AN: If you could pick any professional to do it, so if you could pick a doctor or nurse or a physio or a health assistant who would you pick to teach you the exercises?

[00:13:26]

PT: I think the physiotherapist really, that’s their job isn’t it really?

[00:13:31]

AN: Yes, ok. Erm, what do you think of that perceived exertion scale that we asked you to complete? What did you make of that?

PT: That what?

AN: You know when there was the exertion scale? It was a scale up to 20.

PT: Oh yes.

AN: And we asked you for each exercise to record how hard it was for you. What did you make of that?

[00:13:56]

PT: I found it difficult at beginning until the physiotherapist explained what I had to do.

[00:14:04]

AN: So, what was difficult at the beginning?

[00:14:07]

PT: I'm not sure which ones what number I had to pick you know for each one.

AN: Well what was your understanding of the…

PT: Once she explained, [00:14:19] I realized you know she wanted you to do it in the middle really rather than…

AN: When you say in the middle, [00:14:29] do you mean, what do you mean by that?

PT: The moderate one.

AN: Yeah.

PT: Yeah. So. But do you mean that [00:14:41] you had to be working hard?

AN: Hard yes, within that range.

[00:14:47]

PT: Yeah.

AN: Because the idea behind the exertion scale is that it gives us an idea of how easy or how difficult your finding the exercises.

PT: Yeah.

AN: And obviously, we've go through your exercise guide book today, a lot of the scores remain the same.

PT: Yeah.

AN: Is that because you perhaps made sure that you didn't change? Or is it just coincidence?

PT: Just coincidence I think.

AN: Yeah?

PT: Yeah.

[00:15:19]

AN: Okay. [00:15:20] Okay but you know for example if you if you were finding things really difficult you should be recording a higher?

PT: Yeah. High number. Yeah.

AN: Given those perhaps it wasn't so clear at the beginning how to use that scale. [00:15:35] Do you think there's something we could've done differently?

PT: No, I don't think so, she explained it on the phone, [00:15:48] when I asked her some questions.

[00:16:00]

AN: OK. Would you have preferred a different way of recording how hard you found things? Did you find that scale a bit…

PT: No, once it was explained.

AN: Once you got used to it?

PT: Yeah.

AN: OK, so were you able to perform the exercises regularly at home?

[00:16:20]

PT: Yeah.

[00:16:22]

AN: Did a family member or a friend support you in doing that?

PT: No, I did it on my own.

AN: You did that on your own. And what motivated you to do them?

[00:16:34]

PT: I did it more or less just after dinner you know. Yeah, earlier afternoon.

[00:16:42]

AN: But what made you think I can need to do this or rather than just go over sit down and watch some telly. What gave you that drive?

[00:16:54]

PT: Knowing I had to record it.

[00:16:56]

AN: Yeah.

PT: So, yeah.

AN: Yeah. Do you think…

PT: Right I should get up and do it now.

[00:17:04]

AN: Do you think that now you've finished the study you'll continue doing exercises?

PT: Yeah. I've been told I have to by my *[excerpt deleted to maintain confidentiality]*. I have to keep it up.

AN: And is that because they… what do they think about the exercise?

PT: They think it's doing me good.

AN: They think it's doing you good. Do you think it is doing you good?

[00:17:23]

PT: Yeah, I do. Yeah.

AN: Was there anything that helped you to exercise?

[00:17:31]

PT: What motivated me?

AN: Yeah, I guess so. Or even on a practical level.

[00:17:36]

PT: Just because I want to get moving.

AN: Yeah so it was that [00:17:40] self-motivation to be able to do more.

PT: Yeah. To be able to do more. Yeah.

AN: What did you, how did you find the weekly phone calls [00:17:56] that we offered?

PT: They were ok.

AN: Were they helpful or did you find them annoying?

PT: No. They were helpful. Yeah. Knowing that somebody were checking up on you.

AN: Yeah?

PT: Yeah

AN: And I guess, [00:18:10] did you find it a good opportunity to ask questions?

PT: Yeah.

AN: ‘cos I guess you explained that [00:18:18] our physio…

[00:18:22]

PT: Yes.

AN: …talked you through the exertion scale. [00:18:31] OK. Did you find, [00:18:34] so, did you find that the phone call was more helpful just because you knew someone was making sure you're OK?

PT: Yes.

[00:18:40]

AN: Or was it also or was it more was it helpful because erm from a motivation point of view?

PT: Motivation.

AN: You think it was more helpful for that? [00:18:52] So if we didn't offer you the phone calls say say we'd seen you on that first day and said ‘OK well we'll see you in three months’ time’, do you think you'd have done the exercises?

[00:19:03]

PT: Maybe not. [00:19:06] Knowing you were phoning made you do it.

AN: Right ok because obviously you said…

PT: Yeah.

AN: …that you were motivated to do it…

PT: Yeah.

AN: …yourself anyway.

PT: Yeah.

AN: But you think the…

PT: Knowing somebody was checking up on you.

AN: Right ok I see what you mean, ok. So, it was more the phone calls were helpful from a motivation point of view rather than a safety point of view?

PT: Yeah.

AN: Because did you feel unsafe doing the exercises at home?

PT: [00:19:40] No. No.

AN: Was that ever a concern that you had?

[00:19:44]

PT: No. No

AN: Would you have preferred to be doing exercises [00:19:50] in a group or coming to a class or do you prefer doing them at home?

PT: I prefer doing them at home, yes.

AN: And why is that?

[00:19:58]

PT: I can do it when you feel like you've got the energy to do it.

[00:20:08]

AN: So was it the…

PT: If you go to a class sometimes you’re at that point of a day you’re not feeling too good.

[00:20:12]

AN: Mm hmm.

[00:20:19]

PT: When you can do it at home in your own time…

AN: Yeah.

PT: You get up and do it when you feel…

AN: Yes.

PT: …feel you've got the energy to do it.

AN: Yeah. [00:20:29] Good, good. [00:20:37] Were there any exercises that you found particularly difficult or strenuous?

PT: The sitting up one, I found that the hardest of the lot.

AN: Would you have preferred not to have done that at all?

PT: No, because I think that helps with your legs.

AN: Yeah.

PT: Yeah.

[00:20:58]

AN: Did any of the exercises…

PT: It is the hardest one of the lot.

AN: Did any of the exercises, did you think ‘why have they put this in?’?

PT: That one.

AN: That one. But what you’re saying is that you actually you found it helpful?

PT: Yes, I did, very.

AN: Did you enjoy doing the exercises?

PT: Yeah, I did. Like I said I used to go to the gym so exercising isn’t a problem.

[00:21:30]

AN: And what was it, was it actually doing the exercise [00:21:33] that you enjoyed or was it after doing them the sense of accomplishment? [00:21:40] What was it?

PT: When you finish, you know you've done something.

AN: Yeah.

PT: Yeah.

[00:21:50]

AN: OK. What did you think of the initial, the first exercise 1 which is essentially the walking. What do you think about?

PT: The walking? OK.

[00:21:57]

AN: Yeah?

[00:21:59]

PT: I found that hard at first because like I said a struggle with me legs. But that's got easier.

[00:22:06]

AN: Mm hmm. [00:22:13] Did you em did you find the extra visit you were offered helpful? You know when we brought you in?

PT: Yes. She give me the weights to put on my legs [00:22:26] and er changed one or two exercises.

[00:22:31]

AN: Did she change it to make them harder or make them easier?

PT: Make them harder I think.

AN: And what did, how did you feel about using the weights?

PT: Alright.

AN: Was that, you didn't mind using them?

PT: No.

AN: Were they easy enough to put on?

PT: Yeah, they were. [00:22:47] Yeah.

[00:22:51]

AN: OK. What did, what, [00:22:52] how did you find being asked to go and do more difficult versions of each of the exercises? Would you prefer just kept doing the same ones?

[00:23:04]

PT: No, I found it alright. Yeah.

AN: Did it make sense to you why?

PT: It did.

AN: Why you're…

PT: Yeah. Yes. [00:23:10] I was finding the others a lot easier.

AN: Yeah. Yeah.

PT: So, she made them a bit harder so yeah.

[00:23:15]

AN: Yeah, yeah. And hopefully that was helping you…

PT: Yeah.

AN: …get better…

PT: Hopefully, yeah.

AN: …Hopefully. Erm, OK, You obviously there were a couple of issues you had during the [00:23:37] period because there was a bit of trouble with your ankle wasn’t there?

PT: There was, yes. I broke my ankle last year.

[00:23:46]

AN: Do you think some of the exercises were making it…

PT: Yeah, I think that one [00:23:53] where you had to stand up on my toes. I think that was the one first she changed that and I sat down to do that one and I found that easier.

[00:24:05]

AN: Did you have any more…

PT: It didn't hurt my ankle.

AN: Oh good. [00:24:10] So you went from doing a harder version of exercise to an easier one?

PT: To an easier one. Yes.

[00:24:16]

AN: Did you find that was…

PT: Yes.

AN: …helpful?

PT: I did yes. It helped with my ankle, yes.

AN: I mean we really tried [00:24:27] with well, with the exercise program to be very flexible…

PT: Yeah.

AN: …and pragmatic. [00:24:32] And work around the person as an individual. It sounds like that was helpful.

PT: Yeah. [00:24:42] Yeah.

AN: Did you find it easy enough to contact us? [00:24:50] I mean I don't recall you actually phoning us during the period.

PT: No I didn’t.

AN: Is that because you just didn't feel you needed to?

[00:24:56]

PT: I didn't need to. No.

[00:24:58]

AN: Did you feel comfortable though that you could have?

PT: Oh yes.

AN: Or did you feel, did you feel a bit isolated?

[00:25:03]

PT: No no no, I knew I could have if I wanted to, yes.

[00:25:13]

AN: What are your thoughts on exercise for patients with, for people with kidney trouble or older adults in general? What do you think about it?

[00:25:23]

PT: I think it’s a good thing.

AN: Do some of your do… [00:25:27]

PT: Won’t do me any harm.

AN: …do some of your friends keep active like you?

PT: Yeah. Yeah.

AN: And do you encourage each other to keep going?

PT: Yes.

AN: That's good. That’s good. [00:25:41] Well no it's it's obviously we've spoken about the activities you're doing, the swimming and the line dancing. I mean these are all that that's all activity and exercise.

PT: Exercise yeah.

AN: And it's great it's great. It really is. Did you start, were you swimming before you started our exercise program?

[00:26:01]

PT: Yeah.

AN: Is that something you've done for a long time now?

PT: I've always gone swimming, right from being a child, I’ve always gone swimming.

[00:26:09]

AN: Did you find that doing our exercise program actually gave added benefit in addition to the swimming?

[00:26:19]

PT: Yeah.

[00:26:24]

AN: Now obviously you use a walking stick is that…

PT: As I’m unsteady on my legs.

AN: You’re unsteady on your legs?

PT: Yeah, I don’t feel safe anymore just walking without anything.

AN: How long have you, have you used a stick?

[00:26:39]

PT: About three years.

AN: About three years. Have you found any difference in how steady you feel or is it much the same?

PT: Much the same apart from I can walk further.

AN: You can walk further?

PT: Yeah. My balance isn’t very good.

AN: When you say your balance, you just feel a bit unsteady?

PT: Yes.

AN: OK. Has that been getting worse or is it just been the same?

PT: No, that’s been the same.

[00:27:09]

AN: And you mentioned how you have a stair lift at home?

PT: I do.

[00:27:13]

AN: Have you tried using the stairs since in…

PT: Yeah.

AN: …this period? Have you found it any different or is it still difficult?

PT: [00:27:18] It's still difficult.

[00:27:25]

AN: Sorry about that. So, the main benefit for you has just been that you feel like you can walk a bit further?

PT: I can, yes.

AN: And maybe a bit quicker than you used to?

PT: Quicker than normal, yeah, quicker than I have been.

AN: Have you noticed any change in just how you feel about yourself or is there not been any difference?

[00:27:50]

PT: I feel, I don’t know, feel better in myself, just that I’ve got the shakes.

[00:27:58]

AN: What do you mean?

[00:28:01]

PT: If I'm holding a cup I’m shaking.

AN: Currently?

PT: Yeah.

[00:28:08]

AN: How long has that been?

PT: About 12 months.

[00:28:18]

AN: Have you seen someone about it?

[00:28:20]

PT: No.

[00:28:22]

AN: So is that because you get nervous or…

[00:28:26]

PT: No. I don't know. No. I don't think so. Just that I don’t think, it’s my arms that’s really weak.

AN: Right. [00:28:35] Oh so it's when you hold it, when you're holding something?

PT: When I’m holding something I feel like I'm like…

AN: Because of the weight of it?

PT: Yeah.

AN: So have you noticed any difference during this period? Is it still the same?

[00:28:47]

PT: Same.

[00:28:51]

AN: How about your mood? Has that been any different?

PT: Mood? I’m alright. Yeah.

AN: Yeah. Was that problem beforehand?

PT: No.

AN: OK. Is there anything else you'd like to discuss about the exercise program or the study in general?

PT: No, I'm just enjoying doing it.

AN: You did?

PT: Yeah, I did.

[00:29:13]

AN: Would you give would you encourage…

PT: Somebody to do it? Yeah, I would. It is helpful.

AN: Do you think, I think you mentioned and correct me if I’m wrong [00:29:29] you sometimes I think you commented previously that you had trouble with energy levels? Is that fair?

PT: Energy, yeah, yeah. I haven’t got much energy.

AN: Has that changed at all during this study or is it still the same?

[00:29:43]

PT: It's getting a bit better with the exercises. I feel like I want to do more.

[00:29:50]

AN: Yeah. So just I guess to finish then and thinking about the future, [00:30:07] with regards to activity and exercise? What are your plans?

[00:30:14]

PT: I'm going to try and keep doing these exercises as long as I can. Just keep going.

[00:30:22]

AN: Do you think, [00:30:23] had you not taken part in this exercise program, would you have got into doing more exercise?

[00:30:30]

PT: Well I’d have tried to do more swimming.

AN: You would have tried to do more swimming?

PT: Yeah.

[00:30:36]

AN: OK. [00:30:38] And for the, your experience of the study and everything you’ve been asked to do, is there anything you think that should be changed for a bigger study?

[00:30:50]

PT: No I don’t think so. I think everything...

[00:30:54]

AN: Did you think, do you think that the weekly phone calls are needed?

[00:30:58]

PT: Yes. I think you so, motivation to keep going.

AN: Yeah.

PT: Cos you know if somebody’s going to phone up to see whether you’ve done them or not. It makes you keep going.

[00:31:11]

AN: Good. [00:31:15] Well I guess if there's nothing else you'd like to say, just to say…

PT: I’m ok, thank you.

AN: …thank you so much for taking part. [00:31:23] And yes yes, just thank you.

PT: [00:31:28] Thanks for being so nice.