

## Interview data related to themes from post-programme interviews with participants in the *Living with Dialysis* programme

### 1. Content

#### 1.1. Coverage of issues

“... you are, you know, on the right track here.” (Peter, line 41)

“I thought it was very good because it was very simple, it was very simple and uh, the way it was presented, it would have answered a lot of the questions that I had and the way that I felt right at the very beginning.” (Elizabeth, lines 54-56)

“I think for someone that did have a young family and had to think about stopping work and the financial problems that would come that would come their way. I think it would have been very helpful.” (Elizabeth, lines 96-98)

“... all four sessions covered all the things that that I've suffered with.” (Peter, lines 213-214)

“... it's just learning to understand why you [are] anxious and then trying to calm yourself down and realize that I actually I've got nothing to be anxious about. I'm in good hands and I'm going to be OK. And they discussed that in one of those videos, and I thought that was pretty good the way that was done.” (Elizabeth, lines 234-237)

“I think the topics were perfect because, as I said, I think a lot of people, you know, being unsure and having a little bit of, you know, mental health issues and stuff. I think it's really beneficial. To get it out there.” (June, lines 238-240)

“I liked the fact it came from different angle each time as well because you can... I'm sure everyone on dialysis can identify with part of each of the people involved, if not all. So, like, I thought about that from that person, but I don't feel like that, or I feel like that from that person, so there was something there for everybody.” (John, lines 39-43)

“And the other thing that's good about that video was about, that mindset that we have sometimes that you say, 'well, I'll wait till I feel better and then I'll do this', you know? And that was exactly where I was. It was like, yes, I know I want to do shared care at my centre, and I've been preparing my table since I started doing haemodialysis back in October, so I felt pleased with that, but I felt I needed to move on to my next step, which was obviously putting myself on and taking myself off and doing dressing changes and stuff like that, so I kept on saying, 'oh you know, no, no, no, I'll wait until I feel .... Oh no, I feel tired tonight, no, no, too tired. I've got a headache' or you know? So, I think...but once I did actually think, 'right, OK', I walked in and said, 'right', to the nurse or the other worker, 'right. I'm going to put myself on tonight' you know? And I did it, and then I felt good. So I think I probably watched hers a couple of times because that, just so happened that particular one, really resonated with me that particular week.” (Carol, lines 71-92)

“I really liked how you, sort of, you had a theme, a couple of themes throughout the four weeks. The whole thing about getting stuck. I think that's a really good theme to, sort of,

focus on, because I definitely feel like that is how I have felt over the last few months.”  
(Carol, lines 121-124)

“I like the fact that, you know, there's a good, broad spectrum of experiences of some of the problems that people come across when they start haemodialysis and it's quite nice that, these things came up and I said, oh, it's not just me, this is what people are obviously other people are going through so.” (Carol, lines 139-143)

### **1.2. Personal stories**

“... the way it was broken down, it covered every single problem that I've gone through, it really did, but I think the key thing was that it was personal stories. But the way it was presented, it wasn't too personal, if you get what I mean, you could associate with, I certainly did, every single person you had on there, I had every one of those problems.”  
(Peter, lines 114-118)

“I thought they were interesting, and it's good having different people from different walks of life doing it, again so everyone could identify with them, so that was good.” (John, lines 99-100)

“So, these are real people with real feelings about real situations that are going on in their life around dialysis and, you know, their kidney failure. So yeah, that was good, even though it was like a cartoon. You know, they're true stories from real people. You just didn't put their real faces on. There weren't acting.” (Elizabeth, lines 337-340)

“I think perhaps the older guy. Was it the older guy who was a bit annoyed at first and didn't really like [inaudible], yes that was like me, yeah, I think I identified more with him because it's, dialysis isn't something I enjoy and, again, its making the most of, as it were, rather than, and just accepting rather than... I don't know, it's a means to an end, I suppose.” (John, lines 50-53)

“And then, what I liked was there was a really good mixture of different case studies, the different people that you covered in different backgrounds and all quite different to who I am as a person, but it was quite nice that, even though my story wasn't the same as theirs, there was at least one or two things that they were going through that I can say, well, yeah, that's definitely me as well, you know ...” (Carol, lines 128-133)

“... that came through on the audio [that the narrators are dialysis patients] it's that connection, it a very authentic, I felt, anyway.” (Peter, lines 276-277)

### **1.3. Exercises**

“Really surprised and shocked when I saw exactly what it was because I didn't realize that you would have to be actually physically doing these exercises, whether mentally or physically. Do you know what I mean? So it was right. Yeah, I was. I was really impressed. Yeah, I wasn't expecting that. I thought it might just be, you know, another tick box exercise. But it was more than just a tick box exercise, wasn't it?” (June, lines 27-34)

“Like, doing these exercises, it was kind of quite refreshing and quite relaxing. And you didn't actually realize, you know, if I just sit down and breathe, and, you know, do some of the exercises, you can actually get relief, and you can feel better about yourself. It could, you know it, uplifts your spirit.” (June, lines 39-42)

#### **1.4. Suggested missing content**

“... did, at any point, any of them discuss the fear of death on dialysis? Because that's been one of my big fears, actually dying while I'm having dialysis of a stroke or anything like that or my blood pressure dropping so rapidly, which it has done, like all the bells are firing up ringing and they come along with the oxygen and I'm just, I think I'm going to die [...] it's my biggest worry” (Elizabeth, lines 162-169)

“And I do know that people do die when they're on dialysis and they die waiting for a transplant, and so that is my probably my biggest fear, I suppose.” (Elizabeth, lines 191-193)

“Because like I say, if you're showing that video, those videos to a pre-dialysis patient, you certainly don't want to mention fear of death.” (Elizabeth, lines 374-376)

“You'd have to tread very delicately with it because like you said, you wouldn't want to frighten people, but it is a, it is a real fear. It is a major anxiety problem then with that so, I think you just, you just have to tread very lightly there I suppose.” (Peter, lines 404-406)

“You know, you could possibly put something in saying that there will be times when the bell rings on your dialysis machine. This is what happens, blah blah blah. But you may feel fearful. However, you have a team of professional nurses around you who know what they're doing and just to put people's mind at rest, maybe that might be something that you could do, because that's what I didn't know, you know and that's it.” (Elizabeth, lines 394-398)

“No, not that I can think of [other aspects of dialysis that should have been included] ... I don't think all problems of dialysis will be solved by the videos. My problem is not being able to go away and have it at other centres. Because of COVID, they stopped that, and, going away for a long weekend and having a dialysis, say, near my mum's house, or near my friend's house. See that would increase my quality of life. But that's not something the videos can help with. I think the videos are fine for what they do.” (John, lines 112-120)

## **2. Format**

### **2.1. Video and cartoons**

“... the way you've done it, it's perfect for remote people, you know, if there isn't that service available, I found it really helpful, yeah, I really did, even though I'd already had the therapy, with a psychologist.” (Peter, lines 55-57)

“I think that you hit the nail on the head with it because it comes over as very personal, but not directly, you weren't staring at somebody's face, and the cartoon-type-based video is, often it kept it informal, but the fact that you've got these real-life stories, every single week I've been through all of those problems” (Peter, lines 102-106)

"... I think that format, it's perfect." (Peter, lines 124)

"... it [cartoons] didn't quite appeal to me because I like I, me personally, I prefer animation than a cartoon. So, if they were more kind of robotic kind of people. That attracts me more so than a cartoon. If you see what I mean, or even a, you know, even real live, you know, demonstration... Yeah, yeah, an animated person, kind of." (June, lines 89-97)

"...the videos are quite accessible, and I thought it was a good way of doing it, because people will watch a video in a way they wouldn't read a brief, or three sides of paper or three screens' worth of gumph. So, I think the video idea was good." (John, lines 37-39)

"I really enjoyed them. I've made a note here thinking that I really liked the way that you used animation" (Carol, lines 30-31)

"I felt that the animation was good, and I think it was a really good choice of an approach to animate it because I think then people... have, how do I put this? People might be more engaged in it because they're not seeing... real people [...]. You know, we all as individuals have a bit of a bias when it comes to other people. So maybe it's quite nice to have it as an animation because then it's sort of it maybe takes that bias away." (Carol, lines 35-39)

"And also, it's because it's animation, it wasn't done jokingly, but it had a bit of, you know, a lightness of touch to it. So it wasn't sort of, you know, depressive or anything, you know. So, I think the animation was a good choice definitely." (Carol, lines 45-47)

"I can't really say anything that I thought, really, I mean, I'm going to say, this is me being very picky, and this is me with my working as a project manager in digital advertising hat on, I sometimes felt that the audio quality of the videos could be improved." (Carol, lines 85-88)

## **2.2. Text**

"... I found it, even though I was taking notes, it, sort of, made taking notes a lot easier to be honest with you. With the video, you're engaged with it, but with that text there, I think it just reinforces a little bit of, actually this is what the video is about and what their experiences were. And yeah, I, and again, it wasn't pages and pages of text, was it, it was brief, concise and to the point." (Peter, lines 325-329)

"I liked the layout of it because you know, not everybody is a good reader, so if you can't read that well, the video, it's self-explanatory too, so I think that's really good, whereas I like reading, so I'll read everything on that page and then watch the video." (June, lines 162-164)

"I mean, I read it and I got it. You know, I didn't read it and say, oh, what are they trying to say here? You know, I was, for me, it was good reading material, yeah, so I don't know who wrote that." (June, lines 172-174)

"Yes. Professional. So yeah, it's very professional. So yeah, and I think it's needed as well, especially for kidney patients, you could even put these in pamphlet forms even." (June, lines 177-178)

"I think that was fine because you got the video as well. If it had been just text or just video, I don't think it would have worked as well, I think, the mix was quite right actually [...] Yes, for a lay person like me it was perfectly understandable, yes." (John, lines 138-140)

"Yeah, that [the text] was great. That seemed to work. It was really nice to have a bit of a mixture of video stuff, you know, and also written stuff as well that you could make notes from. So I think that that was a good sort of, yeah, there's a good combination, definitely." (Carol, lines 111-113)

"I think you got that [the balance between video and text] right actually. I felt, I think too much text can sometimes have a negative effect, so I felt that there was a right amount of text in between the different videos each week, definitely." (Carol, lines 115-117)

### **2.3. Length of material and programme**

"... because the videos were short, it keeps your attention, if they drone on too long, it's sort of, your mind wanders. So yeah, it was very good, they were short and sweet." (Elizabeth, lines 157-159)

"... having the week in between [the four weeks of the programme] it sort of gives you that time to carry on with normal life, you're not worrying about it all the time, it's giving you a chance to take it in." (Peter, lines 242-244)

"I think it's fine [a 4-week programme]. It's fine. And even if you were perhaps to do it in a group setting, you could even do every other week or something, given you do it in a group setting. You know, just to, as opposed to, space it out, but it's fine." (June, lines 203-205)

"I think if it had been longer without a break, I'd have perhaps lost interest. [...] I managed to look at it every week and see what it was about it. But I think if I had to do it for, say, six months. I'd perhaps have faulted sometimes. So it was good. If you did it again, if you did four weeks, but then have a break for a couple of weeks. [...] it would give people [a chance] to, maybe to try out some of the ideas that they've picked up." (John, lines 145-153)

"... I thought it was great [a 4-week programme]. [...] I think maybe, having done the four weeks, it felt like a really good starting point, but maybe if there was an option for people to do other ones, I think that would, probably I would, I would be really interested in that." (Carol, line 102-105).

### **2.4. Personal contact with professionals**

"I thought it worked well [without personal contact with a professional] because of the delivery, it's very much, I would say being delivered by patients and there's not, no disrespect to professionals, it's not a professional just reading somebody else's story, it comes over as that patients' story, I know it's that obvious that it's actors doing the voices but they come over very personal and it's very engaging" (Peter, lines 267-271)

"I don't think it mattered. I don't mind. And I mean, but we haven't had the other side, so, we haven't had a similar project with clinicians and real humans. So I don't know if I'd be better or worse, but I didn't seem to miss it, I didn't seem to think, this really needs a doctor

coming in on this [...] I don't think it particularly needed one because it's all self-explanatory. I mean, if there was a problem or a query you could always ask your own clinician, couldn't you, I suppose." (John, lines 164-171)

## **2.5. Ways of watching the material**

"I thought it was good because you can do it at your own time and your own pace." (June, line 55)

"I think the fact that you could read about it prior to watching it and then watching it and doing any of the exercises that they encourage you to do. I think for me it was very logical." (June, lines 156-158)

"... it's easy just to take your time and go through one, like some of them were four, some of them were three and stuff, so you could do two at a time, have a break. Then you can do another two. Or you can just do all four of them. You know, in one go. And you know, regularly takes like 20 minutes to half an hour. Depends on how fast or slow you want to do the exercises." (June, lines 58-62)

"I watched them all once, when I first got the email, but then... I don't know, but bits of each I identified with, but there's one, I can't remember which, I didn't really identify with, so I didn't really follow that up. You know, I read it once and listened to the psychiatrist once and then didn't practice one thing because I didn't think it was useful. I couldn't tell you which one that was. But I thought [unclear] he was quite useful what he was saying so, you know, I went back to that one." (John, lines 183-188)

"Yeah, it was fine [repeated viewing]. Because if you like something and you perhaps want to do it again, you can go back to it. It allows you to go back every session, so you could go back every session and then go forward again. So yeah, it was really helpful to have that." (June, lines 120-122)

"Just one [watched again], the older man one, the David one. I watched that again, to see if I could get any more tips from it." (John, lines 106-108)

"I think I watched Margaret's again. I think because, it may have just have been purely coincidental, that the things that she was talking about in her videos really resonated with me that particular week, so I think I watched it over again because I think there was a couple of things where, that I was going through personally, that really... engaged with me. She was talking about making a bold move, the whole thing about making a bold move, that was really good ..." (Carol, lines 66-71)

"What I find myself doing is actually going back through some of the exercises obviously, I think the beauty with those is, that they're not long, they're not boring and the same with the videos from the patients. You're captured and your mind doesn't wander because you're focused in on it and, like I said, we've all been there where if things sort of drag on a little bit, you sort of switch off, but the timings I found were absolutely perfect." (Peter, lines 134-139)

"I would watch them all the way through, so it's probably, I think probably, obviously it was, it was four weeks wasn't it and there was a main introduction video for that particular person, you know, be it Margaret or the other people, Jayden, things like that, David. And then there was the three follow-on videos for those people identifying the three tools that they were trying to use to help improve things. So yeah, I watched those through at least once or twice, making copious notes and stuff like that and then I would sit and think about how I could apply those things to my things that I'm going through at the moment, so I probably spend a good hour or so each week on watching the videos, making notes, and I think. Then obviously, I think, you can't really quantify, but then you would spend time during the week after watching the videos almost like subconsciously processing it and then maybe applying what you'd learned to what you would go through like being at the head centre or whatever, or being on the machine. So I think even though you might spend time just engaging with the videos and making notes and stuff, I think there's a lot of time that you actually spend just physically, you know, mentally processing the information which is really useful as well." (Carol, lines 49-63)

## **2.6. Time spent on programme**

"I watched them, I did them when I was on dialysis for dialysis, funnily enough, I because I knew I wouldn't have any interruptions from telephone calls. Probably I would say, each part probably about 45 minutes, something like that." (Elizabeth, lines 126-128)

"Well, I did a couple in bits and bobs and then I'd done the whole session [one story and three explainer films] and it took me about 25 minutes to 30 minutes and it was OK because I dedicated my time to that." (June, lines 76-77)

"I was able to follow them [the explainer films]. I can't give any examples but, I tried some, and I didn't try others." (John, lines 83-84)

"About half an hour." [spent watching videos and doing exercises] (John, lines 103)

## **3. Personal benefits of participation**

"... we've all been through an awful lot and, as I said, I've certainly come out the other side of it, and I've relived a lot of it, through those sessions. And yeah, I personally I thought it was fantastic, yeah." (Peter, lines 34-36)

"I've used some of the some mechanisms on that week two, to actually help myself of it and you see when she was feeling pretty crappy and things like that, the first place she went to was the fridge, and I was doing exactly the same thing. So now I still go to the fridge, but I actually wait those five seconds and ask do I actually? And I've lost a few kilos since that, I really have. [...] I thank you for that because that certainly helped me a great deal. It really has. It's got me down my BMI ... to be active on the list, on the transplant list." (Peter, lines 297-305)

"[trying to lose weight to qualify for transplant] it's lot of frustration and it is very stressful. And I said, thankfully, that week two sessions that we've done with regards to you know diving into the fridge when you when you're anxious or you've got the worries that you

want to divert, you know, honestly, it helped me massively really, and I have got to the point now where I'm quite a way below, you know, below the BMI cut off, and I put down to, honestly, that week two session, I really do." (Peter, lines 447-452)

"I think, was it David, the last one who, he, sort of, what is it, there was a lot to do with acceptance and change in the David one, and he was getting angry about having to sit on the machine and go along and do stuff, you know, things like that. So that was really helpful for me because it was like realising that I just need to maybe reframe how I thought about the time and actually, think about it as my time, I can go along and do whatever I fancy, if I felt like doing some work, or watching a film or even listen to a podcast, you know, so. That was really helpful." (Carol, lines 133-139)

"I had to just to say finally, it came along at a really good time because I was really struggling, mostly with acceptance of being on haemodialysis, because previously, up until last year, I'd been on home peritoneal dialysis for about 18 months. And that was going really well, but unfortunately, I got peritonitis a few times, so they had to take my catheter out and put me on haemodialysis, and that was something that I'd really been dreading. So, this came along at a really good time because I was really struggling mentally with having to get used to going to the centre three times a week and all those sorts of things like that and not having the independence of doing PD at home." (Carol, lines 143-151)

#### **4. Applications**

"I think as soon as a person starts dialysis. Prior to dialysis, yeah, they would have a few of these, I would say, conditions or symptoms perhaps, but I think as soon as you start dialysis, it's important then, because some people end up on dialysis as a shock to their system. You know, they go to the hospital, they go to a check-up. Or they fall ill, and they're just put on dialysis. So it's an instant shock or change to their lifestyle, so it's really hard to come to terms with it. It's not an easy thing. Even though you, you know that you're going to have dialysis. When it actually happens and you start to experience it, this is where all of these emotions that are covered in your program will come into play. So I think it's kind of important as soon as, so many people may not feel it's for them. Especially if they're not on dialysis, but yes, they are kidney patients. But I think once you start on the dialysis, that's when things completely changed emotionally. So that would just be my suggestion." (June, lines 272-282)

"I think [relevant to] anyone who's on dialysis. Possibly before, maybe it wouldn't be that relevant to people before they start, because they wouldn't know what to expect, wouldn't know if they're agitated, wouldn't know if they take to it like a duck to water. Maybe they don't know what type of dialysis they're actually going to have. And a lot of those things are more relevant to people who actually go to a centre rather than people who do it at home." (John, lines 196-200)

"I think this would have been really helpful for me prior to, you know, just help with, you know, almost part of a package of, when you're trying to make your decision about whether you're going to do haemo or you're going to do PD, whether you're going to do in-center, whether you're going to do at home and things like that. I definitely think some sort of



course like this as a preparation for before you start doing your chosen dialysis would be, yeah, very helpful.” (Carol, lines 165-170)

“... when doctors are deciding that you're nearing the time for dialysis, I think that's a really good time to show that.” (Elizabeth, lines 249-251)

“... hopefully in the future that would be accessible to, you know, new patients prior to dialysis because, it was fantastic because like, yeah, he's like, you might not have all those, all those issues, but I can guarantee you're going to have at least half of them, you've got at least two of the four at least.” (Peter, lines 118-121).

“... regarding the pre transplant thing I think that's quite an anxious time for people as well when they're put on dialysis and you know, they're hoping to get a transplant. That could be quite an anxious thing because you've got to go through quite a lot of tests to be fit enough to have a transplant. And you gotta meet that criteria. You gotta meet criteria for weight. You gotta have good veins. You gotta have a stress test, now, they're doing another scan. So you've got to get through through all that and if you don't get through that, they won't put you on. So that some people think people think you get kidney failure can just get a transplant. It's not that easy.” (Elizabeth, lines 428-436)

“Oh yes, it has to be, I think so. Yeah, because, you know, when people say dialysis these days, they tend to forget that we have PD patients and they are suffering the same symptoms as us because they're having a form of dialysis, so a lot of PD patients get left out of dialysis. And I think they should always be included.” (June, lines 190-193)

“a lot of them actually do home dialysis, they don't really come in centre to dialyse, so they should always be included because they're going to have similar symptoms to us. [...] I just notice that, you've only got haemodialysis here.” (June, lines 195-200)

“I thought it was really good and I think it is beneficial to get that back out into the community. I think it would be really beneficial, I don't know, you know, whether units, could, you know, perhaps have these kind of group sessions or exercise sessions? Perhaps after dialysis or in between their dialysis. So I think it would be a great thing for the kidney community personally.” (June, lines 42-46)

“I think it's good for you to be able to have at home and also in a group setting.” (June, lines 63-64)

“I do think there is a need for this type of thing, because it's not out there and a lot of renal patients are just left on their own, aren't they, just to get on with life and,, you know we don't have enough social support workers and things like that, so to have this, I think, to have this in a kind of group therapy would be fantastic.” (June, lines 262-265)

“I would just like to say that I just found everything really useful. And I think it's a fantastic project and it should be out there as soon as possible. I hope it doesn't take another year or so.” (June, lines 258-260)